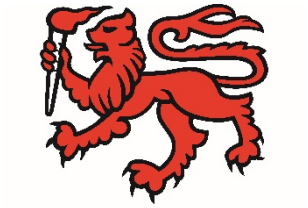

Experiences of public space built environment connectedness and the autism spectrum

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Ethics Approval No. H0015145 – Tasmania Social Sciences Human Research Ethics Committee, 3 September 2015

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Preface

A personal beginning

For Cristen and Mary

'No' is an answer that Cristen can easily provide, but when asked 'can you tell me why', her response is likely to be more of the same, possibly with an even deeper tone and with a more commanding emphasis. Pursuing the question or not respecting her response has the potential to transform the situation to a point of no easy return, to a place beyond where most of us have ever been, where reason and rational thought as we know it are not present. Understanding what provokes this response, what leads to Cristen's discomfort, anxieties, and meltdowns is impossible for outsiders, difficult for family, and complicated, stressful, worrying and sometimes threatening for Mary. To observers, Cristen can seem an undisciplined child and for her extended family, Cristen is hard to understand and difficult to get to know. For Mary, besides all of the daily challenges, the emotional anguish and the mental and physical exhaustion, Cristen is a daughter whose future is something to worry about and to try to prepare for.

Cristen is my niece, diagnosed with autism. Distance has meant that I have had limited opportunity to get to know her and limited opportunity to support Mary. For thirty years I have been working in the field of architecture, providing architectural answers to both residential and commercial questions. But I now realise that for thirty years I have never considered the experiences of a person with autism in my responses to these questions, and when I searched for design advice or guidelines that might be able to assist, I found a gaping void. I knew that autism was not uncommon but admittedly, I knew little about it. My sister-in-law's daily struggles to leave the house with Cristen however are real. Their worlds are narrowed to set routines and safe places. Activities outside of home have to be carefully considered. Outings and places designed to be exciting and fun for all children have to be assessed, screened, tempered and more often, completely avoided. Why? Why does Cristen have difficulty in her world-space, and why as designers don't we understand or even consider that these difficulties exist?

I have long been cynical about the way in which we provide architectural answers to built-environment access for disabled, or, as I now prefer to describe, *differently* abled people. The codes and guidelines are there, waiting to be implemented, but their scope is limited and their application typically occurs as a secondary response with a 'gotta-do-it' attitude rather than an overall informed and embraced design solution. Unless counselled otherwise by particular clients with particular needs, our answers manifest in lifts, wheelchair ramps, disabled access toilets, tactile floor surface indicators, and braille and universally recognised signage that is installed for the lifts, ramps and disabled toilets. The guidelines provided are constantly reviewed and updated, and we are assured that they have been formulated with the advice and assistance of people whose personal experience can accurately inform

needs and expose difficulties with the built environment. Once our guided designs are complete, boxes are ticked by authorities to deem compliance and to comfort us in the knowledge that we have satisfactorily considered diversity in the population we are designing for.

For those whose needs or differences are addressed by these codes of practice there appears to be some progress toward an accommodation of diversity, however, it is the gaping void of missing information that is troubling. The absence of any recognition of neurological difference is blatant. How can we claim that our design responses are well considered when there are a significant number of people that are not even considered in the pages that provide disabled access codes of practice? How diverse therefore are our understandings of diversity, and why in 2016 is there still a need for people to isolate themselves and to limit their exposure to the built environment?

I do not think of Cristen as disabled, but for her the built environment is disabling. Like Cristen, the answer to 'can you tell me why?' is one that cannot be easily answered. In trying to think the problem through, I am deluged with considerations that are deep-rooted, complex, professionally and personally confronting, multi-layered, multi-faceted, and seemingly impossible to combat. Like Mary however, I need to try to gain a level of understanding, to attempt to untangle processes and practices to find some sort of answer, and to make small headway toward easing access to the built environment for Cristen and for others who experience things differently.

Prologue

A Golden Record for Autism

The spacecraft will be encountered and the record
played only if there are advanced spacefaring
civilizations in interstellar space

Carl Sagan 1977

After a short introductory discussion the dynamics changed. Stuart's darting eyes and anxious body language calmed and he began to impart information and share stories. As I listened I began to realise that he understood very well the purpose of my research, but at the same time I was being advised, expertly, on the challenge I was up against. It was our first meeting as participant and researcher. I intended to deliver equipment and discuss details for the fieldwork. This was the meeting where personal comfort levels were revealed and negotiated and where I could hopefully provide enough information to make the participant's fieldwork activities enjoyable rather than onerous. When Stuart relayed the story of the Golden Record I was floored. 'Your research, it's like the Voyager spacecrafts and the Golden Record*',* he said. I didn't understand and I asked him to explain:

> The Golden Record is the recording that was sent with the Voyager spacecrafts in the 1970s; it's carried in preparation for the possible discovery by alien life. It's a recording of things that humans decided should be communicated to alien beings. Imagine the challenges experienced in piecing together the messages and information inscribed on the record. The people involved had huge difficulty deciding what to include and how to include it. Imagine the challenge of thinking about how to explain things to another being that doesn't have the same fundamental understanding of concepts for comparison and reason. Imagine the challenge of deciding what might be useful when you have no idea of the ways that mental processing might occur. How do you explain the concept of time or distance if there is no common point of reference? How do you communicate when the foundations of communication are unknown?
> (Stuart meeting 1, paraphrased quotation)

NASA launched the Voyager spacecrafts in 1977 with the Golden Record fixed to the side of each craft as ‘a kind of time capsule, intended to communicate a story of our world to extraterrestrials’ (Jet Propulsion Laboratory 2018). The records contain images in analogue form, and music, sounds, and greetings as audio. ‘Each record is encased in a protective aluminium jacket, together with a cartridge and a needle. Instructions, in symbolic language, explain the origin of the spacecraft and indicate how the record is to be played’ (Jet Propulsion Laboratory 2018). The very act of understanding what is inscribed on the casing of the record and the methods for unlocking the information inside, is set against great odds and assumes that the discovering aliens will share some commonality of neurological and physiological process. And if by some miracle this first obstacle is overcome, the possibility that the information on the Golden Record itself can be interpreted, understood, and have any meaningful translation is equally questionable.

Stuart’s analogy sounded extreme, or was it? Could there be insurmountable differences in cognitive processing between people on the autism spectrum and their ‘neurotypical’ peers that seriously challenge or even eliminate the possibility for common understandings? Like the committee determining the content of the Golden Record, had I provided sufficient and appropriate guidance for the participants in my study? Could I assume that our agreed, shared understandings might actually be the same or at least similar? And could I then responsibly interpret and evaluate the information they provided?

The obvious and encouraging difference between Voyager’s Golden Records and my research was that participants were not alien but human beings who occupy a place on the spectrum of diversity in the human race. I was communicating with people with comparable biologies using a common dialect of written and spoken words. At our disposal was a vast amount of

information and discourse—scientific, anecdotal, and illustrative—that addresses and attempts to understand the autism spectrum, and pronounced evidence of different forms of advocacy describing varied forms of lived experience and demanding inclusion for those deemed atypical.

This small contribution to a Golden Record for Autism, therefore, is backed by odds that have sound prospect for success.

The individual tracks inscribed on this record, introduced in chapter 5 and revealed and engaged with in depth in chapters 6 and 7, are forms of academically-inflected advocacy—attempts to gain better understandings of autism so that the record's protective jacket can be removed and the contents can be shared. The first action however, is to explore the state of being human that is autism and seek to understand where differences might lie so that information sharing can be better understood and inherently more meaningful.

Contents

PRELIMINARIES

Abstract

Experiences of public space, built environment connectedness, and the autism spectrum

Recent research has highlighted the importance of the built environment for supporting the needs of individuals with autism and their caregivers, yet little of that work has considered the significance of built environment connectedness as a factor in the relationship between access to public space and social inclusion. This study aims to uncover the operative environmental characteristics that influence feelings of connectedness in public space and to contribute to ongoing research and discourse that interrogates notions of *equal, normal,* and *universal* as applied to the built environment. This work investigates the theories, policies, and practices that constitute urban design and its socio-political responsibility to provision the rights of all people with access to, and occupation of, public space.

The research includes a review of literature and discourses about urban design and autism, and about the neurological and physiological factors that facilitate connection to environment. It is also ethnographic and participatory and includes stories shared by five people with autism who engaged in novel fieldwork and semi-structured interviews to provide empirical evidence about their experiences in public spaces. Participant contributions are enlisted—first to expand understandings of the meaning of connectedness by working with and through a lens that privileges

neurodiversity and, second, to question the epistemological foundations and practices that inform and shape urban design. The study introduces two novel ideas: the *Golden Record for Autism*—a powerful metaphor signifying the need for epistemological shifts; and the *score of experience*, which helps people to describe feelings of connection to environment.

Deploying these ideas, the research challenges dominant perceptions about, and thresholds related to, what is "normal", and foregrounds the prevalence of ableism. It exposes the pervasive epistemological impact those two ontologies have on the provision of equitable public space.

Ultimately, then, this investigation evidences the need to accommodate neurological diversity in public spaces. It advances several novel suggestions about how those who shape the built environment can work to more effectively recognise difference as part of the spectrum of normal. It suggests that there are opportunities to make *adjuvant spaces* in which more people can hear the voices of neurodiverse individuals, can make space for change by creating and adopting new neuro-spatial languages, and can make space for difference by provisioning new and better city forms.

PART I

INTRODUCTION

chapter I

space
experience
spectrum
connect
autism
urban

The tragedy is not that we're here, but that your world has no place for us to be

Jim Sinclair

(1993)

1.1 The autism spectrum

1.1.1. A different way of being

In his presentation to the Toronto International Conference on Autism in 1993 Jim Sinclair stated, ‘your world has no place for us to be’ (Sinclair 1993). Autism self-advocate Sinclair viewed his world experience with autism and, by association that of others, as outside the experience of what is often referred to as the *neurotypical* majority. The ‘world’ Sinclair ascribes to others is both material and psychological. It includes both people’s inner workings and all things for which they are responsible. It is in such a context that I apply Sinclair’s statement, understanding urban form as a result of human endeavour and therefore as part of the world that excludes Sinclair and a significant proportion of the world’s population. I use the term ‘urban form’ intentionally to invoke all associated semantics—the shape and appearance of everything urban, and everything that brings those things into being. In my reading, therefore, Sinclair was suggesting that urban form presents barriers to inclusion for people with autism.

The term *neurotypical* (NT) emerged circa 1990 to identify ‘persons with typically developing cognitive processes’ (Barnbaum 2013). It is a term that carries significant cultural, political, and ethical preferences (Brownlow 2010). The implications of those preferences are discussed in chapters 2 and 3. Sinclair suggests that the cognitive processes used by people with autism to understand, interpret, experience, and navigate through world-space are instinctively unfamiliar to neurotypical people. Experiences of autism, Sinclair contends, are foreign phenomena for most people and, equally, for people with autism or those who are *neurologically diverse*, the neurotypical world is commonly incomprehensible.

Sinclair's presentation, entitled *Don't Mourn for Us*, laid out a profound and poignant plea for people to recognise this dichotomy and acknowledge that autism is not something that is going to change or something that can be altered so that a *normal* person can be discovered within. Rather, he emphasised that autism is simply an alternative way of being and that those who experience that way of being can never find comfort nor fit within a world-space created by and for "most people". Sinclair's plea resonated. He invited listeners to value and embrace autism and urged parents to 'care, teach, interpret and advocate' for the 'alien' children who had accidentally landed in their lives.

> Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person—and if it were possible, the person you'd have left would not be the same person you started with. (Sinclair 1993, p. 2)

Sinclair's assertions are challenging. They simultaneously present a key to ideas about equality and inclusivity and, seemingly, a dichotomous foundation upon which to build them. How can there be resolution between those disparities when the gap is subjective and experiential and so profoundly and intellectually misunderstood?

For the decades preceding 1993, through movements based in equal opportunity and equal access, and alongside other disability rights advocates, parents, campaigners, professionals, and researchers sought to strengthen equality provisions for individuals with autism. They were endeavouring to

break down ideas about "otherness" by trying to work representations of *difference* into the web of *normal*. A culminating and significant milestone for these movements was Mace's 'blueprint for maximum inclusion of all people', the advent of Universal Design (UD), produced in the early 1990s (The Center for Universal Design 2008). Perceptions about what constitutes *normal*, Mace asserted, require a person to be 'perfect, capable, competent and independent'. He argued that such a state of being was impossible and that all people were or at some stage of their lives would be subject to dis-ability. Advocates of Universal Design foundationally assumed that degrees of ability were, in fact, part of the normal state of being. Universal Design was, then, an attempt 'to reduce the physical and attitudinal barriers between people with and without disabilities' (The Center for Universal Design 2008).

The "necessary" transformation advocated by both Mace and Sinclair had to be located in cultures and understandings that pervade attitudes about what constitutes *normal*. It had to infuse epistemological underpinnings and foundational approaches. Warranted was a paradigm shift.

At its core, Universal Design was a step in the right direction. It was a shift away from the notion of *disabled* to a notion of *differently-abled,* away from a mind-set that quantified *ab-normal* to a mind-set that identified *normal* as a broad and varied category and enables people to recognise disability as part of the normal spectrum of human experience; simply to recognise it as a different way of being.

Through almost five decades of campaign however, this step has not resonated as profoundly, nor permeated as extensively as equality necessitates. There has been change and there is continued progress toward more inclusive epistemologies. Activists' voices endure, research advances, and autistic auto-biographers help to improve others' understandings of

autism, but those understandings have not yet infiltrated and shifted the ableist paradigm. Hamraie (2012, 2013a, 2017) suggests that the failure of Universal Design to actually improve inclusion for people with disabilities lies in its foundational and contextual assumptions, its heavy focus on access, and in the ensuing universalisation of the bodies that it endeavours to accommodate. 'Following anthropometry's history demonstrates that UD has responded to the normate template by re-conceptualizing research design methodologies and standards of data interpretation rather than simply changing its sources of evidence or the intentions of its practice' (Hamraie 2012, p. 6). Understandings about what disability is and resultant Universal Design provisions are tied to varied conceptions of disability as measured against the normate and importantly, through attempts to accommodate the broadest range of people, those conceptions have lost sight of the specifics of disability. The Universal Design narrative has in fact evolved to be 'disability-neutral: the focus is not on disability but rather on everyone' (Hamraie 2017, p. 34/59 Introduction), and understandings about who 'everyone' is, are confounded by the normate premise. Ongoing consultation and continued feedback from the users have been consistently overshadowed by attempts to accommodate the broadest range of them (Dolmage 2005). Hamraie (2017, p. 39/59 Introduction), in line with critical and crip theory advocates, argues that Universal Design neutralising of disability has allowed emphasis on 'the environmental construction of disability oppression over the embodied experiences of disablement'.

Thus, notions of *different*, *normal*, *equal, able,* and *universal* are still defined by "otherness". Campbell (2008, p. 1) posits that the focus remains on 'disablism' which operates by means of a 'set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities' (Kumari Campbell, 2008, p. 1). In addition, this focus embeds efforts for reform within

perspectives of otherness rather than shifting to ‘what the study of disability tells us about the production, operation and maintenance of ableism. As a consequence, and in parallel, our collective approach to creating and maintaining the built environment has not evolved to improve understandings of the needs of people with autism. Many such people feel disconnected and remain isolated from public places and what they can provide.

Experiences of autism among urban shapers are neither well understood nor adequately considered in processes involved in forming urban spaces. Policies, guidelines, and socio-cultural controls are still encumbered with *othering* epistemology. To challenge and to start to redress this imbalance it is crucial to better understand experience of autism in urban spaces. With improved awareness and knowledge, processes can be challenged, epistemologies evolved and, ultimately, better urban form can be provided. In the next section I begin my part in this process by documenting what autism is.

1.1.2. The autism lens

Recognised and well-respected autism self-advocate Temple Grandin has contributed significantly to autism discourse and acts to enlighten neurotypical people (2002, 2007, 2009b; Grandin, Peterson & Shaw 1998). Grandin’s numerous writings and presentations illuminate her unique perceptions and experiences. They explain processes of thought, physiological, and emotional reactions and interactions with people, animals, and environments. Her direct and articulate manner has been instrumental in processes of information transfer, and provided insight and access to a perspective that helps to colour the spectrum.

> … words are like a foreign language to me. I translate them into full-color movies, complete with sound, which run like a videotape in my head. When I was a child, I believed that everybody thought in pictures. Not until I went to college did I realize that some people are completely verbal and think only in words. On one of my earliest jobs, I thought the other engineer was stupid because he could not "see" his mistakes on his drawings. Now I understand his problem was a lack of visual thinking and not stupidity. (Grandin 2002)

This narrative from Grandin eloquently locates the neurotypical majority. Grandin explains her ability to visualise rather than verbalise as an asset to her work and, in doing so, illuminates how a typical approach and a typical cognitive ability, or an inability to "see"—a condition fundamental to the majority population—can actually be a handicap. Significantly, information provided by Grandin and Sinclair continues to reveal the intricacies of the autism spectrum, together with stories and advice from a growing number of other self-advocates, plus empirical research. Contemporary autism scholarship challenges conceptions of the past. In her challenge, Yergeau (2010, pp. 1-6) to typical writings on autism states,

> The typical autism essay is neurotypical' … 'defensive' … 'a sealed jar without holes poked in the lid. It's an intellectual vacuum … I have been passively constructed into autism—by discourse. I have been passively constructed into aspiedom—by discourse. My other autistic commonplaces—or identity markers—have also been shaped or spawned by discourses: stimdom, speechdom, lack-of-eye-contactdom, patterndom, take-everything-literally-and-then-somedom.

Broadened discourse embracing alternate perspectives and intersections with disability, race, queer and transgender debates now positions the experiences of autistic people within the complex and overlapping contexts of discrimination, identity debate, and minority oppression. Through these discourses, the recognition of autism as an identity rather than as a pathological condition also helps people to 'recognize that it is not a biological or natural property but an elastic social category both subject to social control and capable of effecting social change' (Siebers 2011, p. 4). Contemporary autism discourse is work to position difference into the realm of the normal, but without an objective to normalise. Rather the objective is to surface discussion and to evidence foundational misconceptions and bias, in order to unpack and deliver critical understandings about the genealogy of ideas about what is 'different' and 'normal'.

Using Grandin's methods, it is likely we can locate ourselves and better understand what questions need first to be asked and addressed to improve understanding—if and when we pictorially visualise the idea of *normal* as an amorphous shape that both absorbs and expands the autism spectrum, rather than as a unified position on a linear spectrum that is polarised from another called *abnormal,* the voices of advocates and the experienced can be given more space to resonate. The spectrum allows for 'overlap between once disparate classifications' and is described as a 'device for translating and aligning the multiple interests of autism researchers, clinicians, therapists, parents' and people with autism themselves (Thomas & Boellstorff 2017, pp. 5-6). The device itself, however, is contested. By many, the lineal spectrum is criticised as a 'deficit model', which (a) medicalises and stigmatises, causing—like all social metaphors and conceptual models—tensions between diagnostic categories and lived realities (Thomas & Boellstorff 2017), and (b) impedes the scientific and philosophical progress of the understanding of the phenomena themselves (Dinishak 2016, p. 1).

The ‘autism spectrum’ metaphor and the binary characteristics used to describe the experience of autism—typical/atypical, mild/severe, high functioning/low functioning, and verbal/nonverbal—institute a paradigm that ‘has fundamental consequences for notions of disability, diversity, and normality’ (Thomas & Boellstorff 2017, p. 2). It is criticized as a model that creates polarity and one that categorises and ranks deficit, thereby, reinforcing standpoints of ‘othering.’ Yergeau (2010, p. 6) contends that autism binaries ‘construct a very unreal, very neurotypical, very us/them reality’.

Debates about and criticisms of diagnosis and definitions of autism are critical but too many for this thesis, and I rely on discussions above to signpost their bearing. These discussions and insights from them expose and stress *deficiencies* in neurotypical understandings. Importantly for this thesis, these debates underpin and submit some explanation for the vagaries and shortfalls of consideration of autistic experiences in the built environment, and they explain why it is imperative to seek individual lived accounts of those experiences. Reliance on authoritative medicalised definitions and categorisations of people for the purposes of shaping the built environment has been, and still is—for most—an incognisant position. As a result many people feel unwelcome.

It is this uninformed position that drives the empirical research undertaken in this work. To understand the task ahead, that position also needs to be understood. Following is a summary and discussion of autism as pathology.

Clinically, autism is identified as autism spectrum disorder (ASD) and described as a lifelong neurodevelopmental disorder. The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) defines autism

spectrum disorder as an ‘umbrella’ term encompassing ‘autistic disorder, Asperger’s disorder, childhood disintegrative disorder, or the catch-all diagnosis of pervasive developmental disorder (PDD) not otherwise specified’ (American Psychiatric Association 2013a, p. 1). Definitions of the four included disorders are varied and diagnosis can be specific to one criterion or can be generalised as autism spectrum disorder.

While some individuals identify with a diagnosis of autism spectrum disorder, others identify with diagnoses of classic autism, PDD or Kanner autism, named after Dr Leo Kanner, who published the first clinical account of autism in 1943 (National Autistic Society 2020). Previous editions of the DSM separated diagnoses for autism spectrum disorder and Asperger’s disorder; therefore, it is common for individuals to identify with one and not the other. First defined by Hans Asperger in 1944, Asperger’s itself has been labelled a syndrome (AS) and more recently as high functioning autism (HFA). Since 1944, definitional detail has moved full circle. Now, using DSM-5, it is again only possible to be diagnosed as being on the autism spectrum, albeit within a broad category of characteristics (American Psychiatric Association 2013a; Grinker 2010).

When discussing autism-Asperger’s definitional changes proposed for DSM-5, Grinker (2010, p. 1) stated that the ‘change is welcome, because careful study of people with Asperger’s has demonstrated that the diagnosis is misleading and invalid, and there are clear benefits to understanding autism as one condition that runs along a spectrum’. However, the diagnosis of Asperger’s is still officially upheld for people who received that diagnosis prior to DSM-5. At the present time, therefore, Asperger’s maintains strong clinical and social recognition. Nevertheless, confusion in common understandings arise from decades of shifting definitions and labels and, probably, because of the vastness of the autism spectrum itself, such that it is possible that some people

diagnosed are ‘nonverbal with severe cognitive disabilities, while others are accomplished professionals’ (Grinker 2010). As a result, when the dynamics of definitional and label change are combined with the characteristics of the condition itself there is increased propensity for misunderstanding.

Citing her resentment of circle diagrams, Yergeau (2010, p. 6), contends that, regardless of these shifting definitional criteria, neurological diversity cannot be described in terms of genres or boundaries:

> I can’t be placed within an all-defining circle or even within overlapping circles, and I’m going to project (however mindblindly) that others can’t contain their identities within a bounded, two-dimensional 360 degrees either, no matter how many shiny arrows radiate from the circumference. Communities aren’t static, rigid, and bounded entities as the circles would have us believe.

Thus, outside of clinical definitions of *autism spectrum disorder* there exists varied opinion on appropriate terminology, especially where associated with negative connotation. Many terms and words associated with the history, description, and stories of *autism spectrum disorder* carry social stigma and judgement. For example, the term “disorder” implies a lack, incapacity, or irregularity. The DSM-5 medicalised positioning sanctions a ‘list of deficits, impairments, limitations, and negatively valued deviations from behavioural norms (e.g., little or no eye contact, failure to initiate or respond to social interactions) and repetitive or stereotyped activities (e.g., spinning objects, echolalia, hand flapping)’ and this stance is problematic (Dinishak 2016, p. 2). Besides othering, focus on the negative can distort focus on the strengths of autistic people; it both limits scholarship and concentrates focus on token aptitudes and capabilities (Dinishak 2016).

As well as eliminating the obvious potential for insult by using the term *disorder* and similar terms, I mean to move beyond such stereotype. In this thesis therefore, unless they are words used by others, I refer to autism spectrum disorder as 'autism' and Asperger's disorder/syndrome as 'Asperger's.' Where appropriate I discuss other terms to surface meanings.

Even with definitional criteria, a typical clinically defined autistic identity is difficult, if not impossible, to describe because autism is a neurological way of being that cannot be seen and because autistic idiosyncrasies are environmentally determined—a concept I discuss in more detail throughout the thesis. As some of the participants who worked with me on this study noted, once diagnosed, a typical autistic identity can also be difficult to assume; a person may not have clear understanding of their autism *differences*. Arguably, this limbo of identity occurs when those with autism do not recognise themselves in the 'official' descriptions of autistic identities provided to them because those descriptions are, as discussed above, part of the anti-normate evolution—they are concepts devised and described by non-autistic people. Those engaged in contemporary discourse question whether there is such a thing as a 'typical' autistic identity and ask, also, why is it necessary or even relevant to determine one. The workings of our—Western—social, political, and medical systems, however, require that categorisation and diagnosis be established, and this is done by means of relative and comparative definition. By definition, DSM-5 describes the following characteristics to be symptomatic of autism:

> Autism spectrum disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviours used for social interaction, and skills

> in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behaviour, interests, or activities. (American Psychiatric Association 2013b)
>
> In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. (American Psychiatric Association 2013a, p. 1)

DSM-5 outlines the extent of diversity within the diagnosis and documents an evidence-based assertion that autism symptoms 'fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms' (American Psychiatric Association 2013a, p. 1). Autism Spectrum Australia (ASPECT) (2020) refers to these symptoms as 'challenges' noting that, 'the word spectrum reflects the wide range of challenges that people on the spectrum experience and the extent to which they may be affected'. These challenges can be broadly described as sensitivities to environmental factors both tangible (built or physical) and intangible (social and cognitive). They can cause confusion, anxiety, disorientation, and physical pain. Change and unpredictability can heighten and intensify sensitivities and commonly communication deficits exacerbate them (Bogdashina 2003).

After much research, speculation, and debate there are no agreed causes or definitive theories about causes of autism, and there is no "cure" (Autism Spectrum Australia 2016). There are several behaviour-based treatments for varied challenges specific to individual assessments and these vary depending upon location, availability, the age of the individual, and the

dominant philosophies held by those in consulting organisations. ASPECT currently estimates that one in 70 Australians, or 360,000 people have autism (Autism Spectrum Australia 2020). The Autism Research Institute based in San Diego cites 2019 statistics for the diagnosis of autism in the United States to be one in 59 (1967-2019). In the United Kingdom, prevalence is estimated at 1 in 100 (National Autistic Society 2020) and again figures of around one in 100 are cited by Autism Europe (2019) which comprises a collective of 90 autism organisations from 38 European countries.

It is commonly reported worldwide that the prevalence of autism is increasing (Leonard *et al.* 2010; Matson & Kozlowski 2011). Less well established is whether changing methods of diagnosis and an increase in awareness influence reporting methods and affect statistical outputs; it may be that there is not an actual increase in autism's occurrence (Matson & Kozlowski 2011).

Addressing the debate a decade ago, Leonard *et al* (2010, p. 548) concluded that an increased prevalence was 'largely unquantifiable', and cited 'changes in diagnostic criteria, decreasing age at diagnosis, improved case ascertainment, diagnostic substitution, and social and cultural influences on the overall effects on prevalence, including the role of an ASD diagnosis as a gateway to funding' as influencing factors.

After reviewing available literature, Matson and Kozlowski (2011) reached a similar conclusion, stating that although there had been a definite increase in the prevalence estimates of autism, the increases could not be wholly attributed to a true increase in occurrence. While the literature they reviewed did not refute the possibility of a rising demographic, Matson and Kozlowski (2011, p. 423) again cited as likely contributors to increased prevalence

various changes to diagnostic criteria, increased awareness, and testing at earlier ages.

Irrespective of diagnostic semantics, what remains indisputable in discussions and debates about nomenclature, definitions, and measures of prevalence is that a significant proportion of the population have 'atypical' physiological, social, and environmental experiences. The reasons for these 'atypical' experiences are complex and entangled with considerations of neurotypical epistemology, ableism, othering, and identity. Globally there is qualified consensus on how many people are formally diagnosed with autism but, as Matson and Kozlowski (2011, p. 423) advise, unless there is uniformity and standardisation of diagnostic criteria and methods, there can be no reliable statistics on which a definitive comparison can be based.

Significant also, as is evidenced by the participants who contributed to this study is the potential for there to be many people who have not received formal 'diagnosis of their condition'. Of the five participants, two received formal diagnoses in childhood, one in late teens, one self-diagnosed in adulthood, and the fifth is still confused about advice received at the age of 42. In this respect, a publication from the Autism Research Institute (1967-2019) the following statement appears: 'a 2006 study from Johns Hopkins found that only 8% of primary care pediatricians routinely screened for autism. Lack of familiarity with the screening tools was the primary reason. If your pediatrician isn't seeing what you see, don't wait for him/her to come around.' Thus, the actual experience of autism is likely more widespread than statistics indicate.

In addition to the aforementioned debates, there is broader concern with scientifically based, medical approaches to diagnosis. The application of medical labels and subsequent categorisation of people into clinical boxes, or

circles as Yergeau (2010) describes, creates an inert and potentially stagnant field of inquiry (Imrie 2001). Grinker (2015) suggests there is danger in approaches and processes that promote biomedical standardisation. Unless concerted efforts are made to keep the boxes open and the spaces dynamic, clinical labels will keep them closed. Biomedical practices and methods can work negatively by retaining and binding social identities and creating stereotypes, making it more difficult for attitudinal changes that might instead, allow a positive shift in perceptions.

> Medicalized approaches to autism, at least as autism is now conceptualized as an expansive spectrum, also risk making a disease out of traits that are likely distributed in varying degrees among the general population, obscuring the positive characteristics of autism that contribute to human diversity and creativity, neglecting the possibility for new forms of sociality to emerge, and diminishing the role that autism can play in forming new social identities. (Grinker 2015, p. 345)

Imrie (2001, p. 233) too warns of the dangers that belie biomedical discourses. Citing a series of papers focused on disability and spatiality, he reiterates the authors' advice that 'such discourses seek to propagate a conception of disability as abnormal, deviant and reducible to the physical and mental impairment or the functional limitations of the body' (Imrie 2001, pp. 233, on Dyck 1999; Moss 1999; Sibley 2001). This practice contributes to the simplification and categorisation of people into the social structures of *normal* and *abnormal*, *able* and *disabled*, and *diseased* and *healthy.* These black-and-white "deviant" divisions regulate socio-cultural positioning and attitudes. Inevitably therefore, built environment approaches and practices—based in and informed by prevailing discourse and attitudes—instate difference, perpetuate inequities, and establish an underlying power

construction (Imrie 2001, p. 233 on; Sibley 2001).

Preceding discussion evinces the value of and need for experientially different contributions to understandings of human diversity and creativity. Sinclair, Grandin and Yergeau are only a small part of a growing and active community of both intentional and unintentional self-advocates: that is, of individuals dedicated to informing the neurotypical general population and individuals who contribute unknowingly to advocacy. Contributions by the latter are largely attributable to increased access to and developments in information technology. Online autism communities have also provided a broader, more informed resource and stimulated more and increasingly in-depth empirical research. Insights shared by self-advocates are helping to perpetuate and widen discourse, challenging the notion that people with autism choose to avoid communication and social spaces because of preferences and aversions to social contact (Davidson & Smith 2009).

It is now understood that individuals with autism are often quarantined from social spaces because of how they deal with interpretation and navigation and with sensory assaults from their environments. Many people who sensorially and cognitively process space differently suggest that public places consistently cause them discomfort (Davidson 2010; Madriaga 2010). Inevitably, therefore, unpleasant or painful bodily experiences leave as the only option self-exclusion from public environments. A compounding problem is that, unlike mobility and sight "impairments," autism is invisible and evinced only through behavioural differences that manifest as responses to environmental provocations. So, when an individual responds *differently* from others or from what is expected there is little social understanding, often leaving the perpetrator feeling they have no choice but to remove themselves from public view.

Self-isolation by people with autism also relieves the discomfort felt by the "able" majority and enables them [us] to abrogate their [our] civic responsibility to model and demonstrate inclusive attitudes and behaviours, to learn about the spectrum of human difference, and to mitigate exclusion.

Thus, arguably, cycles of self-isolation, ignorance, and ableism continue, consistently marginalising and constricting the everyday geographies of individuals with autism. By *everyday geographies* I mean the routine social and spatial experiences of a person's life, incorporating both physical and human geographic dimensions. This marginalisation extends throughout the built environment, not only in terms of their being end users of built form, but also because their perspectives are rarely considered in practices of built environment design development and built environment research. Correspondingly, there is limited research on the significance of the built environment to support people with autism to access public space and experience social inclusion.

To counter embedded prejudicial attitudes, constrained understandings must be opened up and become pliable and humble. As Grinker warns, remaining closed and being persuaded by a partial clinical perspective on difference is a prescription for *othering*; it promotes division and, in doing so, deters progressive thought. Sinclair, Grandin and Yergeau are part of the community working to counter such division by providing insight and fostering understandings about autistic lives and experiences. Although these more outspoken members of the community are not representative of all people with autism they simultaneously have experiential insight and the capacity to challenge (Bagatell 2010). As Bagatell (2010, p. 33 and p. 50) suggests via investigations into the idea of an 'autistic community', even with 'resistance from both inside and outside the group … [that community] has the power to transform notions of autism'.

> The emergence of the autistic community reinforces the notion that conceptualizations of disability are social constructions that are constantly shifting … Community members ask not just to be included in the social world but demand that human diversity be valued … [An autistic community] does have the potential to challenge health practitioners, parents and society as a whole to confront attitudes towards difference, to consider who has the right to make decisions for others, and rethink what it means to live a meaningful life.

Indeed, as Sinclair (1993) tells us, people with autism are not to be mourned and the suggestion for many is insulting. 'When nonautistic publics mourn and inquire about the why—why would a child refuse a hug?—the why recedes from the rhetorical and moves into the neurological … The hug-avoidant autistic child is reduced to terms of neuronal motion, of synaptic plasticity and mindblindness and sensory disintegration and gut flora' (Yergeau 2018, p. 6/59 Introduction). Given alternative perspectives, once we have accepted difference as part of the spectrum of normal, we can stop trying to cure a disorder and start trying to accommodate difference. Decades of disability rights advocacy have helped to better integrate and to raise awareness about difference and, like any effort to make change, there are limitations, inefficiencies, errors, and inertia to combat, but progress starts by asking appropriate questions of those who have the experience and the vision.

There are extraordinary benefits to be gained from acquiring new perspectives and from understanding and accommodating diversity, and these benefits are fundamental to progress and positive change. Altering attitudes and improving access to urban spaces and urban life for the one in

70 to one in 100 people who experience isolation will benefit their families and carers and their broader network of support, and I contend that it will be of benefit to all. If consulted, people with autism can provide new and enriched visions of urban life and foster creative insight, and in doing can so open up opportunities for improvements to shared places in urban environments. In the process, removing systematic obstacles and providing more legible and diverse environments benefits all urban dwellers.

Urban shapers therefore have much to gain from listening to voices informed by autism experience. However, because of deep-rooted ableist perspectives, realising what is missing and what there is to gain are not immediately apparent. The process of shaping urban spaces includes moral, ethical, and human rights responsibilities—these I discuss in the following section and in more detail in chapter 2—but there remains a lack of awareness about how and why urban places are disadvantageous for people with autism. I want to address that lack in this research. By exploring access to, navigation in, and habitation to public urban spaces by reference to five people with autism and by and investigating their everyday geographies I search for both proficiencies and deficiencies in theoretical underpinnings and practical applications of urban design. On that basis, in the following section I describe and comment upon the discipline of urban design and emphasise the socio-cultural, political, and philosophical foundations that inform the responsibilities and the practices that are—or should be—held by urban shapers.

1.2 The shape of urban space

1.2.1 Good city form and the neurotypical perspective

Cultural and social factors are inextricably woven into the fabric of environments. The five participants who agreed to share their stories evince this entanglement. Their stories are told in chapters 5, 6, and 7. By definition, environments are aggregates of everything that surrounds and influences an entity's being. Therefore, they are assembled from materials of substance, as well as social, cultural, and political conditions. They are tangible, intangible, and virtual. Environments are simultaneously *spaces* and *places*, each of which has a jurisdiction and a political genealogy. Dovey (2010, pp. 7, 3) describes *place* as 'a dynamic ensemble of people and environment that is at once material and experiential, spatial and social' and, when describing *space*, states that while 'a space may have physical dimensions, it is intensity that gives it potency and primacy'. Such intensity is a fusion of social and cultural dynamics that permeate and influence experiences of space.

In turn, Malpas, (1999, p. 30) presents a common theoretical approach to the concept of *place,* stating that it can be 'distinguished from mere location [by] … being understood as a matter of the *human response* to physical surroundings or locations'. I adopt this description and define *place* as a location laden with personal understandings. It has meaning and the meanings attached to *place* are both installed into it knowingly and unknowingly by urban shapers and interpreted through personal individual experience. *Space* is about location; it has physical and material dimensions. *Space* can be considered in terms of time as well as physicality; it 'can be used to refer to temporal duration as well as to atemporal physical extension' (Malpas 1999, p. 23).

Thus, *space* and *place* are not interchangeable terms, but they are tightly linked, sometimes as a harmonious union, and other times as a strained or competing partnership. In chapters 2 and 3 I examine further philosophies and conceptions of *space* and *place* in the context of civic rights—Lefebvre's *right to the city*—and of disability as an environmental construct (de Souza 2010; Imrie 1996, 2000a; Lefebvre, Kofman & Lebas 1996; Purcell 2014).

Environments, and spaces and places within them, are complicated and multi-faceted. They can accommodate, facilitate, shelter, hide, deter, prevent, influence, and encourage. They can be large or small, appropriately sized or ill-suited to the peoples or groups they are serving. It is commonly understood that environments can affect a person's experiences and that the effects can vary in type and intensity. It is also commonly understood that different places invoke varied feelings. What is harder to understand is how environments do this. However, the act of designing and constructing a place—the development of a part of the environment—includes that responsibility. Understanding whom the likely users of places are and comprehending the impacts of decision-making on the experiences of users are fundamental to creative processes at the active edge of development. Significantly, that responsibility includes awareness of the fact that practices involved in designing and constructing an environment include powers to instate meaning into the spaces being created.

On such matters, Massey (1994, p. 22) deconstructs and reconstructs ideas about space and place, noting that 'an understanding of the spatial must entail an analysis of the economy and society more generally', an understanding of the 'geography of power relations', and also the apprehension of the gendered evolution of spaces and places. The development of the urban spaces and places we inhabit inevitably reflects a location's dominant structural forces and in the history of building cities constructions of masculinity are evident and powerful. Dovey (2007, p. 1)

states that ‘the built environment mediates, constructs and reproduces power relations … Places are programmed and designed in accord with certain interests – primarily in the pursuit of amenity, profit, status and political power’. However, clarity in understandings of how environments gain their character and their meanings is abstracted and convoluted because the final realisation of particular spaces or structures is the result of many design decisions carried out by many decision-makers, enacted for the purposes of achieving one in a multitude of possible outcomes. The machinery that frames and shapes spaces propels series of decisions that influence the access, actions, and the reactions experienced and expressed by users of those spaces.

> Architecture and urban design ‘frames’ space, both literally and discursively. In the literal sense everyday life ‘takes place’ within clusters of rooms, buildings, streets and cities we inhabit. Action is structured and shaped by streets, walls, doors and windows; it is framed by the decisions of designers. As a form of discourse, built form constructs and frames meanings. (Dovey 2007, p. 1)

What is this discourse and who specifically determines the focus, the foundation upon which it is based, the themes, the inclusions, and the exclusions? Who determines when the discussion has reached a point where it can be instated as solution and ultimately given form? The decision-makers are many, but I argue that they share a similar perspective and that the meanings embedded into spaces therefore originate discursively from a neurotypical purview.

The politics of form and meaning are as old as the built environment itself. Expressions of power and influence erected in ancient times still stand in the form of Egyptian pyramids, Roman coliseums, Ottoman mosques, Chinese

palaces, and Catholic cathedrals. Such symbols of authority, wealth, power, and doctrine are overt in their structures and monumentalism; their politics and intent are readily interpreted. But, what of ordinary apparently un-political spaces and places? What shaping occurs from the architecture and urban design that frames the quotidian spaces of every-day public life – the city street, supermarket, neighbourhood park, shopping mall, public square, train station, office building, or library?

Dovey (2007, p. 1) also states that the 'design of built form is the practice of 'framing' the places of everyday life', defining 'framing' as 'the construction of a world and a way of seeing ourselves in it – at once picture and mirror … a 'context' that we relegate to the taken-for-granted'. For the framers of the built environment, the context they have at hand—one that mirrors their own experiences—is readily reflected onto and into their constructions. Neurotypical people are advantaged users of urban spaces and built form—effortlessly, consciously, and subconsciously interacting with it, responding to it, and navigating through it—because they share innate understanding of the language from which it was created.

For others, however, successfully operating within an environment conceived and constructed from a partial mind-set is challenging. Twenty-seven years after Sinclair's advice that for people with autism the neurotypical world could be incomprehensible, there has been little, if any, change to the language of urban spaces. While there has been progress toward increasing awareness and decreasing misunderstanding, the translation of these understandings into changes of approach and structure lags.

1.2.2. Urban design and urban wellbeing

Contemporary built environment practice as it pertains to autism has changed little since Sinclair's plea for change in 1993. In July 2017, the UK National Autistic Society, with its motto 'until everyone understands', sought signatures for a petition to create an autism-friendly high street. Their intention was to encourage the 'British Retail Consortium to champion autism-friendly shops and services to its membership, which includes most of the major UK shops, supermarkets and chains' (National Autistic Society 2016). The organisation reported that, in 2016, 79% of autistic individuals and 70% of families living with autism felt socially isolated.

> Public spaces can be overwhelming for an autistic person trying to deal with too much information. Many autistic people and their families give up using shops, restaurants and other high street outlets because they do not find them accessible, and their worlds shrink. These are places other people might expect to visit without a second thought. (National Autistic Society 2016)

Urban shapers give form to cities, armed with lifetimes of personal experiences, buoyed by substantiation of preceding actions, and with some understanding that their practices are part of a wider dialogue. Spaces are formed and given meaning and become places of urban habitation. Markers can be placed at significant historical points where new and persuasive ideas challenged designers and urban shapers. For example, Louis Sullivan's 'form follows function' statement, expressed in 1896 as part of an effort to free architecture from the constraints of classical thinking, spurred designers to pursue beauty through functionality and dispense with decoration. In turn, Ebenezer Howard in 1898 promoted garden cities as a remedy to the perceived diminished quality of urban life in the United Kingdom caused by

the rapid and uncontrolled growth spurred on by the Industrial Revolution. Members of the Bauhaus movement of the 1920s and 1930s sought to reinvigorate the design of everyday items with beauty and creativity and align fine art with craft thereby promoting a more aesthetically imbued way of life for all people. In 1961, Jane Jacobs urged designers to learn from the ordinary and diverse examples of everyday life in cities rather than follow the orthodoxy of preceding more removed and aloof urban theorists. And in 1981, Kevin Lynch asked, *what makes a good city*, and provided a value-laden prescription for the development of 'good' urban spaces.

Designs for the built environment originate from, and both intentionally and unintentionally perpetuate, social and cultural philosophies. Designers and governments will push new agendas or follow convention, reinforce dogma or challenge it, and economics will affect form and drive policy. But one consistent theme that has advanced during the evolution of considered design is greater emphasis upon people, and health and wellbeing of and in the world's urban spaces. As populations rise in number and density of living patterns, as urban centres grow, as space becomes more valued, and as the intensity of experience increases, the importance of locating people at the centre, as the starting point to design solutions, has become more critical. Influenced by past theorists and by cultural philosophical underpinnings and institutionalized forms of guidance, contemporary urban shapers now share a greater awareness of their social responsibilities.

In considering a new theory of good city form, Lynch, (1981) an influential urban planner, advocated starting with a series of questions that would provide answers about people's needs. Lynch stated that the 'fundamental good is the continuous development of the individual or small group and their culture: a process of becoming more complex, more richly connected, more competent acquiring and realizing new powers – intellectual,

emotional, social, and physical' (1981, p. 116). He set out to connect 'human values and the spatial, physical city' and provided a set of performance criteria that relegated settlement—described as an intricate ecological system—to a supporting status (1981). Significantly Lynch's theory put first the actions, needs, wellbeing, and wants of the users of spaces. He recognised the need for flexibility, openness to change and diversity, and saw as fundamental to the health and growth of a city and to the quality of life of its inhabitants the importance of connections—person to person, person to environment and environment to environment.

Lynch's bottom-up approach also encapsulated his recognition that the quality of a settlement was a relative and nebulous thing that could only be determined and truly shaped by its users. Considered a seminal theory, Lynch's holistic attempt to understand the idea of 'good' as it relates to city form continues to influence contemporary urban design dialogue and practice. His detailed consideration of human experience and inclusion of the characteristics of sense, perception, and mental capability into the list of dimensions used to determine settlement quality, are valuable resources and provide counterpoint for my investigation into the experiences of people with autism in urban spaces. Problematic however, is the neurotypical ontology in which Lynch's theory is founded. Conceptions of sense, perception, and mental capability are not only fundamentally dated; they are fundamentally, neurotypically biased.

While I contend that the subject of neurotypical perspective is rhetorical in the context of Lynch's essay, the dimensions he proposed as measures of quality evidence prevailing ontological positioning with holistic intention. Importantly, they also provide scope and encourage discourse on the epistemological approach to determining what is, and what is not, *good city form*. As Dovey (2016, p. 8) states, 'the best of cities are highly efficient urban

ecologies where we can live better with less – where the big issues of social injustice, poverty and environmental degradation can be addressed in part through the shaping of public space'. It is this shaping and the activity of the shapers that I investigate in the following chapters.

1.2.3. The epistemological challenge

The primary matter that concerns me in this thesis is to ask if we can firstly recognise our innately varied experiences of the environment and acknowledge the impact that difference has on our intuition, opinions, and perspectives. Then, if we can recognise the potential power relations at work on the fabric of those relationships, can we better address the built environment needs of different experience, provide for diversity, and create more inclusive environments?

It is easily argued that the generation of sound knowledge occurs through close engagement with the subject matter. When attempting to understand an idea, action or reaction, it is an obvious first step to ask questions that can provide answers or, more importantly, ask questions that lead to others with promise of more detail and simplicity, as well as greater diversity and complexity. What is also necessary is that the questions themselves originate from varied sources and perspectives. As Mostafa (2013, p. 4) states,

> Such exclusion from the mainstream spectrum [of architectural practice] may be due to unique spatial needs and requirements of specific groups, or social phenomena that arise from particular transient or non-transient socio-political circumstances. Such marginalized groups include, but are not necessarily limited to, individuals with special needs and disabilities particularly developmental disabilities with

> nonphysical manifestations … By encouraging research in this area we may create a much-needed body of information and a number of methodologies and policies required to address the architectural and urban needs of such special populations.

Neurodevelopmental disorders are many and complex and such circumstance alone might explain why, for example, building regulations and standards focus primarily on considerations of wheelchair access, lift installations, tactile ground surface indicators, and toilet cubicle size. This situation alone however does not abrogate the responsibilities of designers and policy makers. It is my contention that while more enriched research and diverse interrogation of built-environment equitable access have occurred over the last 50 years, the threads of inquiry falter *at their inception*; the methodologies and policies developed to address diversity in the population originate from under-informed design briefs. Our knowledge base is shaky at the roots. Neurotypical perspectives have disguised and swayed question-making processes and the tree of knowledge is therefore stunted at the very point where the branching begins.

This contention is not new to built environment discourse. The accommodation of diversity in the field of design is much debated. Since the mid-1990s, Rob Imrie has highlighted the building industry's underperformance, citing processes of architectural design, governance, and regulation as obstructive hindrances to inclusivity (Imrie 1996, 1997, 2000a, 2001, 2003b, 2004a, 2004c; Imrie & Street 2009). As Imrie (2003a, p. 47) states, 'the most influential architectural theories and practices fail to recognise bodily and physiological diversity, and there is a tendency for architects to design to specific technical standards and dimensions which revolve around a conception of the 'normal' body'. Likewise, Heylighen, Van Doren and Vermeerch (2013, p. 7) have explored the explicit experience of

users and compared it to the intent of the architect, suggesting that ‘Architects can have specific intentions in mind, but users (with an impairment) may not experience them’. Architects, they contend, default to the ‘normative practices and prevailing frames of reference in society’ (2013, p. 7). Similarly, Tauke, Smith and Davis (2013, p. 8) assert that, ‘designers can no longer exclusively design in their own image … [but] must actively consider the perspectives of “the other” in both general and specific terms’.

It is in the arena of social responsibility and of human, civil, and disability rights that these questions must be answered. Efforts to consider and to minimise the isolation experienced by people with autism must begin by exploring both difference and the difference of experience. Such explorations must consider both the multi-dimensional conflict between access to space and the socio-political epistemologies that inform design choices. The function of space and place as social constructions embedded in power relations, and the subtle but overwhelming role that the built environment plays in this relationship, are part of the epistemological challenges that constrain abilities to provide equitable access and accommodation for people on the autism spectrum. These challenges are discussed in more depth in chapters 2 and 3.

Baumers and Heylighen (2010, p. 1) contend that having ‘understanding of diversity is a key principle in the development of theories, tools and techniques of design for inclusion’. Their investigations involving individuals on the autism spectrum are among attempts ‘to gain a more accurate insight into the diversity of people’s interaction with the designed environment’ because, as they note, people with ‘autism spectrum disorders, for example, due to their particular way of thinking, make sense of their surrounding world in a unique way’ (2010, p. 1). The challenge undertaken in this thesis is to advance that understanding by first soliciting unique insights. Next, is to

interrogate contemporary design approaches, influenced by seminal neurotypically-sighted urban theorists that continue to spur—through incognisant action/inaction—a narrow perspective on inclusion and on the breadth of human experience. I extend discussion about these approaches and the embedded neurotypical perspective that instils biased environmental meanings that are innately unidentifiable and offensive to some users of some spaces. The investigation is designed to answer the following questions:

- How do people with autism experience public urban spaces?
- How do these experiences influence the everyday geographies of people with autism?
- How do these experiences support, extend or challenge contemporary urban design theory, policy and practice?

1.3. Methodology

The aim of this research is to investigate the experiences of people with autism in urban places and to elevate the voices of such individuals by gathering, interpreting, and sharing their stories. It is intended that this research provide opportunity for new self-advocacy for autism in the arena of urban design. The research methods I use are qualitative; there are no quantifiable aspects. The only relevant statistics are those cited in section 1.1 detailing diagnostic percentages.

Writing is arranged into four parts: Part 1, *Introduction*, Part 2, *Literature and Context*, Part 3, *Giving Voice*, and Part 4, *Discussion and Implications*. Through desktop research from varied sources, in Parts 1 and 2 I compile and evaluate information on autism and on urban design. That information provides background for Parts 3 and 4, in which I elaborate on methodology, describe

the research study specifically designed to capture unique experiences, and then share, analyse and discuss those experiences. Part 4 also includes a discussion of participant experiences and advances suggestions about how to make space for change.

Responses to the first two research questions articulated above are best achieved by asking direct and directed questions of the people to whom the experience belongs. Input from people with autism has far greater capacity to ensure authenticity and in doing so make meaningful contribution. One available option was the research method used by Davidson and Smith (2009) and Baumers and Heylighen (2010), who sourced *auti-biographies* to investigate the interaction between people with autism and their environments. Due to the difficulties and complexities involved in accessing willing autism voices this method was attractive; however, I anticipated that the lack of specific autism-built environment material would mean that both information gathering and analysis could suffer from contextual legitimacy. Also, to better represent people's stories I wanted and needed to understand the experience of autism more comprehensively and more empathetically.

The alternative option for work in Parts 3 and 4 was to undertake participatory research and invite people with autism to contribute by providing me with answers to the research questions. Fletcher-Watson *et al.* (2018) contend that, for autism research, participatory research methods 'can deliver results that are relevant to people's lives and thus likely to have a positive impact'. Authenticity, McCloud (2013) advises, can be compromised when researchers 'second-guess the motivations and interpretations of individuals who may view the world very differently'. Authentic perspectives are the 'texture and weave of everyday life' (Mason 2002, p. 1); they are the contextual and nuanced viewpoint this research seeks to elucidate. The answers to questions 1 and 2 can only be subjective. Individual perspectives

colour experience and incorporate the more abstract notion of meaning. The research study undertaken therefore is qualitative and participatory. The participatory, phenomenological method of inquiry determines that the approach used to engage with people on the autism spectrum be highly flexible in method and be reflexive in practice. It incorporates options for choice of method and for personal direction. Flexibility is built into research design processes to allow for the likelihood that individuals with autism will preference different ways to engage, and in doing so provide less guarded, richer answers to the questions.

Enlisting the participation of people with autism is a challenging process. Many individuals are socially removed and are often shaped by ableism to believe that their experiences may be of little significance. It is commonly supposed that the built environment is composed of fixed, unmoveable, objective entities that a person has to learn to negotiate and navigate. As a consequence, adaptation, tolerance, and avoidance have become routine practices and a person with autism often takes on the social stigma associated with being different, of being wrong and ill-fitting, and of believing that their voice is unimportant. The effects of ableism are discussed in following chapters.

Participant stories are presented as exactly as possible, maintaining the context of their conveyance, to try to represent all realities truthfully. What cannot be ignored is that due to possible processing differences there is potential for fundamental contextual misunderstanding and miscommunication. There is a possibility that cognitive and physiological differences cause information to be obscured, distorted, and misunderstood. There is also possibility that I have omitted relevant representations because meanings have been literally lost in translation. Notably, once the stories leave the position of literal and verbatim discourse and move through the

qualitative processes of analysis and discussion the subtleties of neurotypical ontological positioning risk misrepresentation of a participant's reality. What is critical therefore is that there are mechanisms in place to address and attempt to counter obfuscation, misrepresentation, and omission. To such ends, I encouraged participants to take ownership of the research study fieldwork, allowing them to tailor their methods, the way they presented their information, and the way the engaged with me.

The cross-disciplinary nature of this research required investigation into the politics, ethics, and the theoretical underpinnings and lived experiences that permeate both urban design practice and the lives of those with autism. While it is not the intention to make generalizable comment on the experiences of the autism *group* in public places, it is proposed that the joint investigation provide new and generalizable epistemological insight. Mason (2002, p. 1) argues that one of the primary strengths of qualitative research is in its contextual practices:

> it has an unrivalled capacity to constitute compelling arguments about *how things work in particular contexts.* More than that though, while not all qualitative researchers are on a mission to produce 'the general picture' of how things work, the qualitative habit of intimately connecting context with explanation means that qualitative research is capable of producing very well-founded *cross-contextual generalities,* rather than aspiring to more flimsy de-contextual versions.

Thus giving voice to parallel but individual experience within a contextual framework is proposed as a legitimate and meaningful approach. It is used to seek information that is specifically attributable to a particular experience in a particular context, but it is also proposed that any cross-contextual findings

provide greater strength of argument. It is possible therefore to extrapolate a generalizable explanation from a small contextual group (Mason 2002, p. 8). It is the intention that the qualitative methods used in this study follow this format by firstly providing maximum opportunity for the individual voice to be heard, and secondly by exposing and elevating their voices through contextual analysis.

Denzin and Lincoln (2005, p. 21) advise, 'No single method can grasp all the subtle variations in ongoing human experience. Consequently, qualitative researchers deploy a wide range of interconnected interpretive methods, always seeking better ways to make more understandable the worlds of experience they have studied.' The use of multiple methods therefore, especially those used in research involving people on the autism spectrum, are employed in this study to attempt to elicit better and more correct understandings.

1.4 Thesis structure and chapter synopsis

This thesis provides contextual framework for a basic question-answer scenario. The four parts are divided into seven chapters. To respond to the questions identified in section 1.2, it is firstly necessary to introduce and define the subject and its historical context. This work is done in Part 1 and Part 2. Part 3 describes the research fieldwork and includes the analysis, synthesis and discussion chapters. Part 4 is the final discussion chapter.

Preface

Impetus for this thesis is provided in the Preface with a subjective account of motivations both personal and professional. The function of this writing is to explain how the questions emerged and importantly, to expose my own

ontological positioning, to reveal personal values and lay bare potential influences.

Prologue

The prologue provides explanation of the title of this thesis. The dialogue recounts an initial meeting with one participant who eloquently summarised the intentions of my research. The Golden Record analogy is a powerful metaphorical concept that establishes the complexity and challenge of autism-related research. It is a constant reminder of the need for continued and holistic efforts to understand difference and to incorporate those understandings into the built environment so that additional cognitive translation work can be minimised.

PART 1 - INTRODUCTION

Chapter 1

The current chapter has introduced the purpose of the thesis, explains my research perspective, provides a synopsis of the foundational concepts explored, and then sets out the challenge undertaken and the questions asked. Because autism is invisible and experiential and there is largely a lack of understanding about what autism is, this chapter provides detailed background information and provides both clinical definitional understandings of autism, as well as a glimpse into how it is personally experienced. The personal experiences depicted in this chapter emphasise the importance and need for additional autism lenses in built environment research and for incorporation of that research into built form. This chapter provides a foundation for the perspectives exposed in following chapters. The chapter also exposes the relationship between environmental experiences and built environment practice through introductory discussions on

meaning, the notions of space and place, and the epistemological foundations that shape them.

PART 2 – LITERATURE AND CONTEXT

Chapter 2 – Urban space and city publics

Chapter 2 is an exploration of concepts and theories about urban design. It provides discussion on the nexus that underpins the current investigation. Discussion in this chapter explores and exposes the neurotypically-based epistemologies that continue to influence the work of urban shapers. The chapter traces significant design and planning theorists, their contributions to and influence over the idea of what comprises a 'good' urban space. Lynch's ideas on the connection of people to place are explained in more detail, to both interrogate the concepts and to provide a basis for the analyses provided in Chapters 6 and 7.

The historical progression of urban design theory currently locates people as the starting point to design and, its primary tenets are bound up in social and cultural philosophies with more informed understandings about inclusion, yet many people still feel unwelcome in public places. In that chapter, I address the value judgements that occur within this socio-cultural environment and their direct and indirect translations into built form. I expand upon the notion of meaning and the power of decision-makers and place-makers, and explore the subtleties that manifest through built environment processes. Issues of civil and disability rights, ideas about disability as a social construct and their positions in the power game form part of this discussion.

Chapter 3 – The experience of space

Chapter 3 is an exploration of the experience of space. This chapter includes discourse on the psychology and physiology that determines how we perceive, sense, navigate and find our way through space, and on the spatial and environmental cognition used in those processes. I also discuss the relationship between environment and feelings of connectedness. In this chapter I describe how neurological differences in processing can cause the built environment exclusion experienced by individuals on the autism spectrum. This chapter explains how spaces conceived and constructed by typically abled people do not accommodate difference. I argue that the connection of person to place assumed by urban shapers relies upon typical neurological perspective and physiological functioning, thereby discriminating against those who experience space differently.

PART 3 – GIVING VOICE

Chapter 4 – Methodological wayfinding

Chapter 4 is a discussion on methodology. Giving voice to an individual and trying to extract meaning from their situated experience is quintessentially a hermeneutic phenomenological practice. In this research the experiences sought sit literally outside of, and are foreign to my own; I am distanced at the very inception of the neurological process therefore the research methods used are intended to maximise communications. Discussions in Chapter 4 describe the qualitative, mixed methods employed in the research as well as the history of these as they relate to urban design and to autism. In Chapter 4 I provide discussion on the theory and evidence of past methodology and methods. Also discussed is the challenge that ableism and isolation pose to

research participation. This factor is discussed as a determining factor of the participatory methods chosen for the current research.

Chapter 5 – Seeking a Golden Record for Autism

Chapter 5 outlines the design of the research. In this chapter I provide an introduction to the empirical part of the study, the rationale behind the methods chosen, and their intended purpose. The introduction explains the intent behind the research design, which was to allow participants to assume the role of researcher and educator, to hopefully mitigate initial influence over fieldwork observations and the ensuing discussion points, and to empower each participant with an understanding that their determination of what was important was paramount. Ethical considerations concerning the engagement of persons with a cognitive impairment are discussed throughout Chapter 5 because it is recognised as foundational to both the selection and to the implementation of methods.

Chapter 5 also details an account of the actual occurrences and flexibilities in method that were necessary to accommodate participating individuals. These are described in detail to provide transparency and to explain resulting differences in the information presented in Chapters 6, 7, and 8. Due to their varied positions on the spectrum, participants reacted with differing levels of comfort to how they were to engage with the research; actions and activities embraced by some were difficult or intolerable for others. Chapter 5 outlines my approach to each participant, which was to use caution, to try to eliminate discomfort from the outset, and to remain completely flexible in regard to the way in which individuals conducted their own research and recorded their own experiences.

The challenges of the recruitment process are also documented in Chapter 5. These challenges, described in section 1.3 above and in more detail in Chapter 4, exemplify consequences of disenfranchisement that people with autism experience. The challenges are detailed and inform the implications for future research described in Chapter 8.

Chapter 6 – Through Asperger lenses – Part 1 – Ableism

Chapter 6 is the first part of my analysis and synthesis of participant *scores of experience*. Participant stories are grouped into this chapter under the overarching theme of ableism. Analysis and synthesis in this chapter—in part—addresses the first research question about the experience of autism in public urban spaces, and also the second, which queries how those experiences influence everyday geographies. The theme of ableism is investigated under three sub-themes: difference, diversity and discipline.

Participant stories are intertwined under each of the sub-themes to reveal and discuss experiences in urban places. Analysis in this chapter explores how the five participants encountered ableist culture and how they adjusted, accommodated, mediated or resisted it. Participant experiences reveal unique perspectives on, and perceptions of, difference, and how those perceptions affect geographies and activities. Encounters with the accommodation of diversity, or the deficit of accommodation, are also discussed and include direct commentary on Universal Design. The final section in this chapter reveals types and methods of self-discipline used by participants to enable entry and inclusion into both socio-cultural and built environments. The adjustments and disciplines described are physiologically and emotionally personal and subject to both spatial and temporal influences.

Chapter 7 – Through Asperger lenses – Part 2 - Connectedness

Chapter 7 continues the analysis and synthesis of participant stories adding further detail to experiences in urban spaces and to impacts on personal geographies. The *scores of experience* in this chapter are grouped under the theme of connectedness. Again, this work is divided into the three sub-themes; they are disconnection, construction, and connection.

In that chapter, participant feelings of connection to environment are analysed with consideration of a person's social, spatial, and sensorial connections. Analysis includes discussion on the importance of these connections and considers the different ways connection can be achieved. Participant stories reveal that for some people, staying at home is easier than trying to access urban spaces and for others it is necessary to construct either practical or psychological methods that enable or improve access and occupation of spaces. Final discussion in the chapter draws on analyses of participant encounters with the consistency, reliability, predictability, and surety of shared urban spaces.

PART 4 – DISCUSSION AND IMPLICATIONS

Chapter 8 – Making space for autism

Chapter 8 provides discussion on autism, space, place and environment. Here I consider the *scores of experience* revealed in the previous two chapters and discuss participant relationships with ableism and their feelings of connectedness. The limitations of the study are outlined, noting in particular the exposure of only five participant voices with each representing just one position on the autism spectrum.

Making space for autism is descriptive of the path I suggest be taken to better accommodate neurological diversity in public spaces. I advance three ways in which urban shapers can more effectively recognise difference as part of the spectrum of normal and in doing so, influence positive change. I introduce the notion of *adjuvant spaces* in three forms; (1) making space for autistic voices by acquiring lenses to augment vision, (2) making space for change by creating and adopting new neuro-spatial language, and (3) making space for diversity by provisioning new and better city forms.

PART 2

LITERATURE and CONTEXT

chapter 2

Urban space and city publics

... the modification of settlement is a human act, however complex, accomplished for human motives, however obscure or ineffective. Uncovering those motives gives us some first clues to the connections between values and environmental form.

Kevin Lynch

2.1 Chapter layout

Urban space and city publics explores the literature and discourses that are concerned with how urban spaces are shaped. I analyse the genealogy of urban design as a synthesis of related disciplines and practices intended to address the needs of and issues confronting urban dwellers. I examine the politics and processes that inform the conception of and the provision of public spaces. I select and compare seminal contributions to urban design theory, and question what it means to be urban. Discussion in this chapter investigates city publics and urban shapers, their motivations, and the regulatory guidance and controls that informs them. I also deliberate the users of urban spaces, their rights of access to, and use of those spaces. I critically interrogate notions of the *right to the city* and of *public space*, and examine what it means to be atypical in an environment shaped by and for typical people. I discuss ableism as both a material and social construct installed into the built environment through neurotypical approaches and applications.

Analysis is presented in five thematically divided sections. Each section explores a singular suggestion and documents answers to why the experiences of the built environment for people with autism frequently deviate from *normal*. The sections are summarised below. References for the foundational authors that scaffold this work are cited only in the body sections; for brevity and flow they are omitted from section summaries.

Section 2.2 *Connective tissue*, discusses connection as an operative force linking people to people and people to environment. I build on discourse about connection and establish it as a primary theme of my investigation. I advance the idea that, for neurotypical people, connection is fundamental to the cognitive processes used to realise and navigate environments, and to the

socio-cultural relationships that underscore a person's sense of belonging to, and feelings about their environments. I question whether these fundamental understandings of connection can be *universally* applied or whether assumptions made at this elemental level in fact contribute to ableist approaches to shaping urban spaces. Understanding the substance and genetics of connective tissue and what facilitates connection is an essential part of the process of investigating, and of proposing, steps toward positive change.

Section 2.3 explores the notion that *informed design is the generator of good city form.* I define and trace the discipline and practice of urban design from its inception, and document the proponents, their philosophical foundations, and the paradigm shifts that nurture and sustain it. My intention is to ascertain the ethical, moral, and practical parameters that underlie and augment practices involved in forming cities, to evince the relevance and influence of urban design as a discipline, and to expose the neurotypical pervasiveness of urban design philosophies. Section 2.3 consists of four sub-sections: 2.3.1 *Provenance*, 2.3.2 *Roots and milieu*, 2.3.3 *A global perspective*, and 2.3.4 *Seminal urban design*.

In Section 2.4 I explore the suggestion that *access is synonymous with equality*. With focus on public space, the literature reviewed investigates access from the point of view of both the design profession and the user. In sub-section 2.4.*1 Citizenry,* I analyse the objective and subjective meanings of *access* and *equality*, Lefebvre's (1991; 1996) notion of *the right to the city*, and the influences of civil and disability rights movements. Sub-section 2.4.2 *From public space to shared urban space*, exposes the rules that govern public spaces and those that aim to enable inclusion and demonstrates the significant socio-political differences between *space* and *place.* I interrogate the politics of public space and the power that is infused both within and throughout the

intentional process of place-making and within and throughout the routine processes that determine built form. In sub-section 2.4.3 *Equity and access*, I focus on the intentions and manifestations of Universal Design and related movements to review the politics and realities of public social equity and the built environment.

In section 2.5 I examine literature with focus on the subject of difference; writings that both explore and postulate the idea that *difference is fundamental to the spectrum of normal*. I investigate autism, as Sinclair requested, from a perspective of *a different way of being*. Literature reviewed in this section addresses the semantics and semiotics of difference, diversity, and neuro-diversity, able, disabled, and differently-abled. I interrogate normality and ableism, explore the concept of neurotypical, and examine discourse on the condition and experience of autism and Asperger's Syndrome. Sub-sections are: 2.5.1 *Semantics and semiotics*, 2.5.2 *Difference and ableism*, 2.5.3 *Self-expression*, and 2.5.4 *Labels*.

In section 2.6 *Diversity discourse*, under the sub-heading 2.1.1 *Social justice*, I address the subject of diversity and consider discourse on definitions and understandings of what diversity is, and how it is contemporarily addressed. The authors cited propose that there exist tokenistic definitions of diversity and that, as a consequence, the inclusion of diversity into the built environment is deficient. I advance the argument that the improvement of inclusion is best served by gaining better understandings of diversity from the people who experience exclusion.

2.2 Connective tissue

One compelling idea evolved out of my review of literature associated with urban design, public space, and autism. It emerged that each field of inquiry

can be described in terms of the operative forces of *connection*. The connections of *person to person*, and of *person to place* are consistently used as fundamental determinants for the success and wellbeing of people. Without connection, the literature suggests, perceptual and cognitive links are impeded, human relationships are diminished, and environmental experiences deteriorate (Alexander 1979; Bromfield 2012; Davidson & Smith 2009; Kaplan, Stephen & Kaplan, Rachel 1982; Lynch 1960; Salingaros 1998). There is agreement with Hagerty *et al.* (1993, p. 291) who state that, 'We all have a need for meaningful relationships that transcend our separateness'. Authors consistently propose that degrees of *connectedness* determine the strengths of relationships, thereby facilitating experiences of belonging, giving life meaning. They also suggest that these 'meaningful relationships' operate through and within both physical and socio-cultural contexts.

Disagreement is found in discourse that challenges the unchallenged perspectives of meaning, connection, and relationships (Dolmage 2015; Hamraie 2013b; Haraway 2004; Latour 2005; Massey 1994; Silberman 2015; Yergeau 2010). What is deemed meaningful, the importance, the value or the type of connection that is valued or necessary, and the processes and relationships that establish those meanings and connections, are subject to neurological understandings and perspective. The sciences—medical and social—that establish the foundations of those understandings are charged with having derivatives based in assumption, generalisation and ableism. Questioning whose 'meaningful relationships' are being considered, and how and what determines effective connection is a necessary starting point.

Yergeau (2018, p. 14/80 Introduction) states, 'Despite autistic people's increased visibility and, indeed, increased participation in public policy and political advocacy, autistic stories are not the autism stories that circulate, dominate, or permeate'. What is heard, disseminated, applied, and infiltrated

into theories and understandings is convenient and superficial, leaving the sciences stabilised, their epistemologies and ontologies unchallenged. Disassembling the associations and connections that underpin medical and social discourse rhetorics is critical to gaining improved understandings of the experience of autism in the built environment.

Intuitively, relationships can be understood as wholly subjective, but leading literature reveals, they originate by means of innate, more objective cognitive processes. These investigations into the operations of cognitive processing provide insight into the mechanisms and pre-eminence of *connectedness*, especially those studies described by Kaplan and Kaplan (1982), Townsend and McWhirter (2005), Ellard (2015), Sussman and Hollander (2014), and Robinson and Pallasmaa (2015). Writings on urban design and the built environment (Ellard 2015; Malpas 1999; Robinson & Pallasmaa 2015; Salingaros 1998; Sussman & Hollander 2014) describe how cognitive functioning allows for the acquisition, interpretation, and use of environmental information so that spaces can be understood and navigated. Writers considering autism (Bromfield 2012; Davidson & Smith 2009; Mostafa 2013; Silberman 2015) advise that atypical cognitive processing and atypical sensorial experiences are common for people with autism. It is these differences that offer clues to why experiences of the built environment for people with autism frequently deviate from *normal* and to why the provision of equitable public space is compromised. In short, neurotypical understandings and typical neurological mechanism assume and rely upon the users of public space to be cognitively aligned.

Connection requires two-way, reciprocal interaction; it is unceasing, conditional, and personal. In discussions on Asperger's, Bromfield (2012, p. 74) asserts that connection is the sharing of 'language, concepts and understanding' and that those things provide access to our social and cultural

environments. The point of connection between people and their environments is firstly sensory. It is where a person's 'insides (and mind and experience) intersect with the outside (world), where their bodies and sense organs (skin, eyes, ears, tongues, noses) meet the environment' (Bromfield 2012, p. 34). These connections, made both consciously and subconsciously, provide to us our way of being in the world; they facilitate connectedness. When discussing human relatedness, Hagerty *et al*. (1993, p. 293) thus state that 'Connectedness occurs when a person is actively involved with another person, object, group or environment, and that involvement promotes a sense of comfort, well-being and anxiety-reduction'. It is this definition of *connectedness* that I adopt in this thesis and use when analysing the success of the public urban spaces of our built environment.

Principally, this work is a search for the meaningful relationships that strengthen connectedness supported by a comprehensive thematic review of literature, and by empirical research. Stake (2010, p. 111) refers to 'the search for contextual relationships' in a given literature. Here, that search involves considering a range of concepts. The concepts themselves are interwoven but broadly fall into contextual alliances of cognition—spatial cognition and environmental cognition, and geography—social geography, cultural geography and psychogeography. Each of these evinces links through the dynamics of connection. I link my primary areas of investigation—urban design, public space, and autism—by reference to the fundamental imperative for connection. My research questions (chapter 1, section 1.2.3) suggest two lines of inquiry: first, investigation into theories and decision-making processes that determine the final designs for public spaces, and second, investigation into the typical and atypical ways in which people perceive and process spatial experience.

My first inquiry—theories and processes that characterise and define urban design and create public space—is addressed in this chapter. I investigate a series of questions grouped in three:

> (1) *descriptions*: what is urban design; who were the seminal designers and theorists; who are the current influential designers and theorists; and what are their philosophies and approaches?
> (2) *processes*: what is the contemporary understanding of urban design as a functioning and contributing component of the built-environment design process; what forces have shaped current practices; are there power and politics at play in urban places; who are the decision makers, and where does their guidance come from?
> (3) *public spaces*: what is public space; how does a public space differ from a public place; in the process of forming public spaces and places how are the needs of people viewed, incorporated, and accommodated; and, why do we feel like we belong in some public places and not in others?

The second inquiry—analysis of the typical and atypical ways which people perceive and process spatial experience—is addressed in the following chapter both through a normative lens and through the lens of autism. The three areas of investigation for that inquiry are:

> (1) *experience*: how do we occupy and navigate through space; how do our surroundings influence us; and how do cognitive and perceptive processes aid in the acquisition, interpretation, and use of environmental information?
> (2) *autism*: what are the experiences of people with autism generally; and what characteristics of autism influence experiences of the built environment (and vice versa)?

(3) *built environment and autism*: what is the relationship between the experiences of autism and provisions of the built environment; is there a current discourse about built environment experiences of people with autism; and what design practices have specifically addressed differences associated with autism and were they successful?

This exploration of connectedness is a search to determine firstly, whether connectedness is an appropriate or relevant paradigm with which to evaluate the experience of autism, secondly, if it is relevant, how is it conceived, and thirdly, whether the constructs infused into urban spaces and places by people with typical cognitive and sensorial processing provide appropriate connective tissue for those whose processing is atypical. The relationships among the built environment, urban design, public space, experience, and autism that facilitate connectedness are complex and so interwoven that it is not possible to view each relationship in isolation. For that reason I have chosen to investigate the questions noted above—in this and Chapter 3, *The experience of space*—thematically, by means of contextual ideas.

2.3 Informed design is the generator of 'good' city form

2.3.1. Provenance

> Urban design is in fact a mongrel discipline that draws its legitimizing theories from diverse intellectual roots: sociology, anthropology, psychology, political science, economics, ecological, physical and health sciences, urban geography, and the arts; as well as from the 'professional' theories and practices of: architecture, landscape, planning, law, property, engineering and management. Indeed, wherever it can. (Carmona 2014b, pp. 2-3)

As a distinct discipline, *urban design* cannot be studied from any singular viewpoint. It is at once a concurrence and a conflict of practices, a juxtaposition of theories and philosophies that, since its inception in 1956, has not earned consensus of definition (Krieger & Saunders 2009, p. vii). *Urban design* as a label, and as a perceived new dynamism in design, was formulated to combine disciplines into practice/s that could address urban issues unattended at the edges of architecture, city planning, and landscape architecture. In 1956, José Luis Sert, Dean of the Harvard Graduate School of Design, advanced the idea that city planning had necessarily shifted from focus on the 'superficial "city beautiful" approach' and was, by then, concerned with the structure of a city and also 'its process of growth and decay, the study of all the factors—geographic, social, political, and economic—which have shaped the city' (Krieger & Saunders 2009, p. 3). Sert and his contemporaries (including noted urban activists, Jane Jacobs and Lewis Mumford) gathered in 1956 at a formalised academic conference to usher in a new era of urban planning and design. They proclaimed it an 'era of synthesis' centred on a 'respect for all things human' on a renewed scale, one that was less monumentally-based than past models (Krieger & Saunders 2009, p. 5).

Current discourse credits this mid-20th century urban design reckoning as significant and seminal. Although the combining of disciplines done in 1956 falls short of contemporary opinions on what is required to address urban issues, the 'effort to change the subject of design from the individual patron to the collective urban population' is still at the forefront of modern urban design doctrine (Mumford 2009, p. 31). With respect to *place*, this research must be considered within a domain of characteristically Western *processes*. The ensuing discussions therefore are founded in Western axiological and epistemological discourse. They are also relayed with awareness of the

neurotypical standpoint from which they derive, which in the following chapter subsections, to make clear their etiology, remains unchallenged.

2.3.2. Roots and milieu

The methods, values, and principles of contemporary urban design are traceable to the establishment of first settlements (Childs 2010; Ellard 2015). Needs for protection, shelter, and the company of others coupled with the benefits of cooperative industry and defence and the politics of aspiration and power inspired urbanisation and have continued to do so with increasing intensity. 'Neolithic villages and the earliest cities show care in site selection and development, collective infrastructure, public spaces defined by patterns of enclosing buildings, and the patterning of multiple buildings and spaces' (Childs 2010, p. 1). Religious homage and practices, coupled with politics and structures of governance, have driven feats (and follies) in architecture and determined layout and hierarchy of settlements as peoples repeatedly implemented and proclaimed struggles against their mortality (Ellard 2015, p. 15). Vestiges of early enterprises, both those planned and executed in rigid detail and those less-considered and organic, remain today in assemblages and in philosophies that continue to influence modern thought, or as practices and principles that do not easily extract from modern thought.

The definitive *city* is described by some modern theorists as a dated model, a non-existent, now romanticised, and mythical construct of 'civic life represented by piazzas, bridges, churches, and palaces' (Ingersoll 2004). This city conjures visions linked to notions of order and hierarchy, structure for purpose, vibrant public meeting spaces around churches and civic buildings, community street markets, and minimal traffic congestion. Ingersoll goes so far as to state that this idealised city form is dead, now replaced by urban sprawl without evidence of civic consciousness (2004, p. 3). The cities of our

past were founded for smaller populations. By 2018, 55.3 per cent of the world's population lived in urban areas with 23 per cent in cities of more than one million people and these numbers and proportions are predicted to grow rapidly (United Nations 2018). The United Nations (2018) cites growth statistics of 60 per cent of the world's population in cities and 28 per cent in cities of more than one million people by 2030. Urban pressures have, and will continue to increase, intensify, and diversify.

The United Nations (2016, p. 5) contends that rapid urbanization, coupled with globalization, has produced a dysfunctional model of urban development: 'The model is a result of relentless globalization, the unfettered transformation of cities into sources of private gain, a declining attention to public space and community benefit, and rapid technological change which in the end increases connectivity while it diminishes accountability'. Urban design theorists and urban design practices of the 20th and 21st centuries have attempted to address urban dysfunction. Processes and belief systems from the past have been perpetuated and new perspective progressed (Childs 2010, pp. 1-2). Patterns of, and approaches to, urban development through the 20th century provide evidence of prevailing socio-political philosophies. They are also material examples of successive thoughts that reflect shifts from more top-down to more bottom-up motivations and from a focus on the physical design of places imposed with little or no consideration of the broader population to a focus more concerned with communicative action and holistic and humanistic intent.

Urban communities, or cities and towns, are 'built and maintained by a host of agents' (Lynch 1981, p. 40). Lynch proposed that, as primary agents, developers and financiers first create basic patterns in form. The patterns are then 'filled in by the actions of many others, in particular the location decisions of individual families and of firms of modest size, the preparatory

decisions of real estate speculators, small developers, and builders, and the regulatory and supporting functions of local government' (Lynch 1981, p. 40). In essence, this extract from Lynch's work *A Theory Of Good City Form* also delivered a doctrine for caution. It proposed that there are many, often divergent, factors and players involved in making urban communities, and importantly it proposed that most of them act out of self-interest with little perspective on communal prosperity and the collective health of citizenry.

Childs (2010, p. 2) provides a commonly accepted synopsis of urban space progression in the 20th century from early centralised practices to those that are more decentralised. He proposes five 'interwoven threads of praxis' as loose categories of settlement design for this era:

> (1) *Civic design/City Beautiful* and the *Garden City Movement* responded to the squalor and disorder of the turn-of-the-century urban boom, and sought to produce social order and healthy cities with access to nature;
> (2) *The Modernists* and advocates of the functional city sought to organise the city and its inhabitants according to a doctrine of *form follows function* with explicit positions on progress and social morality;
> (3) *Urban Design* promoted a shift from a governmental civic-centred design focus to a broader and more human-centred urban focus;
> (4) *City Design* was used in distinction to 'urban design' to emphasize care for the quality and character of the entire public realm with an emphasis on fundamental human values such as justice, control and vitality; and
> (5) *Townscape and Historic Districts* ... which showed a concern with the scenographic, historic and story aspects of a settlement.

While these loose categories provide only one perspective and are rooted in Western culture, they exemplify the fluid nature of urban design theory and practice and expose its reactionary and subjective character. The proponents of these movements responded academically to their predecessors' approaches, and offered solutions to what *they* perceived to be the socio-economic challenges facing the inhabitants of urban spaces. This aristocratic standpoint is a common criticism of design disciplines 'based upon the idea that urban designers can in themselves analyze and design the built environment for the general good' (Mumford 2009, p. 28).

Decision-makers armed with limited subjective experiences and constrained opinions about what urban spaces should provide appear to have been predicated on idealist notions of how urban inhabitants should conduct their lives and have led the process of making decisions for all. The collective that assumes responsibility for each 'thread of praxis'—or that is retrospectively acknowledged for the undertaking—arguably is not socially representative. Rather, it assumes a social and moral manifesto and members enact that accordingly. Like movements in the fine art, urban design platforms draw in new and popular schools of thought, briefly establishing new and strengthening old inter-disciplinary networks, while discharging the dated and unfashionable. As Biddulph (2012, p. 18) states,

> [urban designers] are not free to do exactly as they want. We cannot ignore what the social sciences tells about the nature of spaces that people inhabit, or how they might inhabit space … Urban designers must embrace the interpretive and very political nature of the context in which they work, and the solutions that they propose.

Urban design remains composed of a loose collective of proponents. Thus it remains relevant to ask who are the decision-makers; what socio-economic and cultural prejudice do they bring with them; and how are they determining what is right, just, valued, and sound for the breadth and depth of an urban population? Can a largely neurotypical urban design collective provide appropriate urban spaces for the one person in sixty who does not experience the world in such a manner?

As Childs (2010, p. 3) notes, 'Much of this debate focuses on what constitutes good (or achievable) city form' but what also must be debated is what constitutes sound urban designers? Childs poses the obvious question—should urban design be formally established as an independent discipline, thereby making it more definable and accountable, or should it continue to operate as a shared praxis among a 'school of professions' articulated by a 'spectrum of roles'? (2010, pp. 3-4). Either way, Krieger asserts that regardless of the current discourse on urban design as a discipline, it is the latter that has evolved (2009, p. vii). Carmona (2014b, p. 12) elucidates this perspective in the following passage:

> Urban design is situated in both place and time, but despite our obsession with the here and now, with the latest economic or political news, the latest governmental initiative, development project or urbanism trend, it may be that our influence today is less significant than we like to imagine. Instead, how we act today is shaped by an accumulated history of experience and practice, by established ways of doing things that change only very slowly and that are still (despite globalization) very place dependent, and by the fact that real innovation in design is rare … This means that urban design process begins long before contemporary development proposals are dreamt up, and these in

> turn build upon a very long history that continues to inform processes of change through to today.

Carmona's argument is clear; urban design is a cumulative, constantly evolving process, but is not easily or radically altered because it is heavily influenced by practices and philosophies deeply embedded in tradition and entrenched in place. The *process* is not necessarily linear, nor is it consistent in its composition. Instead the mechanisms of urban design are complex and multi-disciplinary, subject to social and economic scrutiny, and require specialised multifaceted advice and layered approvals. Urban design undertakings fluctuate in size and in relation to focus, and draw in multiple players across many independent agendas.

In this vein, Carmona (2014b, p. 6) describes the *urban design process* as an 'integrated place-shaping continuum through time' and proposes two foundational contextual factors: 'the history and traditions of place' and, the prevailing 'contemporary polity'. Carmona (2014b, pp. 6,11) also suggests that these factors are subject to four 'active place-shaping processes': design, development, space in use, and management. The final step in his shaping process relates to the influence of social, political, and economic power relationships, which he describes as operating 'like a lens, focusing the processes of urban design in different directions and in diverse and inconsistent ways, and decisively moulding the nature of outcomes in the process'.

Carmona's (2014b, p. 2) *Place-shaping continuum* theory was derived from empirical, retrospective research into how public spaces in the city of London were formed, with the intent of revealing a 'potential to anchor the field of urban design, offering a core for intellectual enquiry and policy/practice innovation'. He has proposed that the mechanisms of urban design are place-

dependent, and that the cultural, political, and geographical characteristics of place will dictate and regulate the *process*. He suggests that urban design is complex and fluid, infused with local values, judgements, and politics, dependent upon multiple decision-makers, and governed by power relationships. His ideas consolidate the bases of a discipline subject to a 'spectrum of roles' and imply a decentralised process *theoretically* open to grass-roots influences. It is evidence of progress incorporating, as Sert intended, the capacity to evaluate a city's 'growth and decay' and the 'study of all the factors—geographic, social, political, and economic—which have shaped the city' (Krieger & Saunders 2009, p. 3).

It is interesting to consider then, what urban design might be like if it were an independent discipline. Might the process of formulating a new paradigm initiate and allow for more rapid change and the interrogation of certain epistemological foundations? Could the result be a more unified and concentrated application of methods to consider diverse populations and more equitable and inclusionary practices? The success of such a paradigm would depend upon the depth of understandings of diverse experiences and the ability to insert such knowledge into all areas of the urban design *place-shaping continuum*. Success would also rely upon unified, consistent and persistent application. The risk of such a model lies in the potential for return to a centralised system where aristocratic urban shapers do not ask for experiential advice from diverse groups of people and instead deliver partial versions of what is deemed apt for all. Somehow epistemologies need to be challenged. The roots and milieux of urban design suggest that the movement toward more grass roots, place-based, and people-centred approaches is more likely to provide strength of understanding and true infiltration of positive change. Challenging neurotypical perspectives by increasing the inclusion and participation of diverse perspectives may then lead to foundational shifts in the knowledge base of urban shapers.

2.3.3. A global perspective

The United Nations (2016, p. 123) cites modernist approaches to the formation of cities as regionally insensitive, narrowly focused, economically driven, and often implemented by inhumane political agendas. Growing international concern for the welfare of urban inhabitants suffering the pressures of market-driven and political agendas instigated the formation of a collective United Nations program. Armed with a new motto of 'a city that plans' replacing the modernist catch-cry for 'the planned city,' UN officials now promote decentralised planning approaches with a focus on encouraging practices that are 'politically engaged, inclusive and empowering, strategic and integrated' (UN-Habitat 2016, p. 123). As a response to rapidly growing pressures on urban space, the United Nations Human Settlements Programme (UN-Habitat) has adopted this bottom-up philosophy as part of a global effort to organise, empower, and influence planning practices, especially in less prosperous cities. The UN 2016 *World Cities Report* (2016) states that 66 per cent of the world's population will live in urban areas by 2050. The report places urgency around the need for a more holistic planning model.

> we stand now at a unique tipping point where our planet is, for the first time in its history, predominantly urban. There is an urgent need at this juncture for new planning visions, strategies, policies and tools that can transform our planet of cities into a planet of inclusive cities. (UN-Habitat 2016, p. 71)

In that work, the word *urbanization* has negative connotation and the practice is pervaded with negative outcome. Indeed, the *World Cities Report 2016* (2016, p. 5) claims that although 'urbanization has the potential to make

cities more prosperous and countries more developed, many cities all over the world are grossly unprepared for the multidimensional challenges associated with urbanization'. Current practices of city making do nothing to obstruct increasing environmental, social, and economic challenges and 'cities are now operating on a … economic, social and cultural ecology [radically different from] … the outdated model of the city of the 20th century' (UN-Habitat 2016, p. 5). What is needed, then, are renewed models for development that foreground people. In that light, the *World Cities Report 2016* cites that its new urban agenda should, above all, 'prescribe conditions that would facilitate a shift towards more sustainable patterns of urbanisation, seeking to achieve inclusive, people-centred, and sustainable global development (2016, p. 6).

2.3.4. Seminal urban design

Approaches to designing urban spaces and places for populations can no longer be approached in isolation. As Amin (2006, p. 1) notes in this respect:

> the sites of civic and political formation are plural and distributed. Civic practices – and public culture in general – are shaped in circuits of flow and association that are not reducible to the urban (e.g. books, magazines, television, music, national curricula, transnational associations), let alone to particular places of encounter within the city.

Likewise, Krieger (2009) contends that new perspectives in urban design are borne out of the incongruous or deficient practices that precede them. Inevitably, the process of change is slow. The size of the task presents obstinate elements of resistance, as does the intricacy of social and cultural threads that bind urban spaces together. Stakeholders' diversity is also a

challenge to the pursuit of progressive ideas and ambitions for urbanism, allowing mediocre responses and enabling influence of groups with private agendas:

> However, rather than wallow in despair about the unpredictable nature of decentralized processes, urban designers must learn to be more effective collaborators, willing participants in true interdisciplinary endeavours, and advocates for ideas not always their own, ideas that have potential to rally others around higher expectations, not expedient solutions. (Krieger & Saunders 2009, p. xii)

As responses to environmental and social pressures, urban design approaches have supported philosophical ideals and political agenda. Mid-century praxes were reactions to modernist attempts to impose lifestyles dominated by the views of elitist planners and designers. Seminal texts by Kevin Lynch (1960, 1972, 1981) and Jane Jacobs (1961) advocated paradigm shifts that challenged urban designers to reinstate the human element into the city by introducing sociological theory as a design fundamental. Lynch published *A Theory of Good City Form* in 1981 to answer the question, 'What makes a good city?' His exploration sought to provide a 'normative theory about the form of cities' and was a 'systematic effort to state general relationships between the form of a place and its value' (Lynch 1981, p. 99).

Jacobs (1961, p. 17) intended *The death and life of great American cities* to be a deliberate critique of city planning practices, citing them as orthodox and harmful *because* of their orthodoxy. Jacobs urged designers to learn from cities and peoples, to seek out the unusual, and to embrace and encourage diversity. In *A Pattern Language*, Christopher Alexander et al. (1977) later analysed and codified how human beings interact with their environments to

formulate a method to maximize the positive impact of the built environment on human emotional wellbeing (Salingaros 1998). In turn, William Whyte (1980) wrote of the value of small urban spaces, celebrating them as dynamic and vital places of exchange that should be encouraged. Whyte also promoted the importance of maintaining and developing urban spaces as social hubs, places that encourage the mixing of different groups and make it easy for them to do so.

Jan Gehl continues the fight for people-centred cities in an effort to improve the health and wellbeing of people and the vibrancy and liveability of urban centres (Gehl 2003, 2006; Gehl, Bundsen Svarre & Risom 2011; Gehl & Koch 1987). Reiterating the calls made by his predecessors, Gehl argues the need to privilege human beings as the starting point of all urban planning practices and to build city spaces that offer a high quality of life. He urges urban shapers to understand that 'the city is not defined by its structures and monuments but by the people [who] inhabit it' (Gehl, Bundsen Svarre & Risom 2011, p. 7).

Considering the inhabitants of cities as indicators of the quality of built form or the success of a city, Gehl's perspectives elucidate the problem at the core of this thesis; if people with autism are unable comfortably to inhabit city spaces then such spaces cannot be defined as offering high quality of life and cannot be seen as having been planned with human beings at the starting point—some people are missing. Adopting this perspective also speaks to the untapped opportunity that lies within collaborative, participatory processes that inform and shape the built environment. The different, varied human perspectives that people with autism can contribute to the process of shaping cities are, then, mostly unrealised.

In contemporary urban design theory, ‘good’ city form has ethical, moral, humane, and physical dimensions. Forming cities and the urban spaces within them are pluralistic pursuits. They embrace activities that incorporate various roles in which urban shapers fluctuate in number, type, and philosophy. With a view to ‘rally discussion’ and ‘spark debate’, Fraker (2007, p. 61) has proposed six “force fields” to describe contemporary urban design thinking about the ‘multidimensional considerations of the city—its layers of social, political, economic, experiential, and aesthetic meanings’. He suggested a flexible assemblage of modes and gave them the titles: (1) everyday urbanism, (2) generic urbanism/hyper-modernity, (3) hybrid urbanism, (4) new urbanism, (5) transformative urban morphology, and (6) urban ecological reconstruction (Fraker 2007, pp. 62-63). Fraker’s motivation was related to pedagogy and in response to the lack of discourse that could assist students to develop theoretical foundations to understand the contemporary position of urban design as a practice. His suggestion came with a qualifier, however: ‘any attempt to identify specific “force fields” in this contested discipline is dangerous and potentially arbitrary’ (Fraker 2007, p. 61).

In discussing Lynch’s *Good City Form*, Inam (2011) recommends redirecting focus to processes that shape cities rather than maintaining focus on form. Inam (2011, p. 275), states that Lynch’s theory ‘was far to utopian to be truly operational in terms of providing concrete strategies and steps for a project’. While Lynch suggests focus on the place between abstract notions of ‘good’ and the narrower considerations of ‘form,’ his overall framework is too comprehensive and too prescriptive, relying on pre-formed understandings that guide aspirations (Inam 2011, pp. 275-276). Dovey (2016, pp. 1-8) advises that cities, urban life and urban agendas are replete with competing ‘desires and interests’ and as such are ‘far too complex for formula-driven approaches’. Dovey’s (2016, p. 8) recommendation is for urban shapers to

forgo attempts to ‘resolve or reduce’ the complexity of the task and to instead try to understand it, to formulate ‘more questions than answers’ in order to provide a sounder basis for action.

Contemporary urban design practitioners are cognisant of the value of first-hand experience, the importance of localised information gathering, the need for tailored response, the fragility of environment, and the diversity of a city’s subjects, but still they are beholden to wealth, politics, and power. Thus, it ‘takes political will to integrate, rather than to further fragment, the built environment of any city’ (UN-Habitat 2016, p. 79). In response to such dominating forces, urban designers must actively drive theoretical agenda and become more influential actors in the pluralist pursuit to provide good city form. Importantly, as staff from UN-Habitat urge, urban shapers must derive the philosophy of a place from its inhabitants. Informed design can only occur with meetings and exchanges among users and designers. Using practices of participatory planning and design and understanding that planning is an ongoing and inclusive process may help reinstate and strengthen the view that urban spaces are places for people. Little wonder, perhaps, that in an interview in 1996, renowned but controversial and provocative architect Koolhaas stated that:

> people can inhabit anything. And they can be miserable in anything and ecstatic in anything … the generic city, the general urban condition, is happening everywhere, and just the fact that it occurs in such enormous quantities must mean that it’s habitable … We all complain that we are confronted by urban environments that are completely similar. We say we want to create beauty, identity, quality, singularity. And yet, maybe in truth these cities that we have are desired. Maybe their characterlessness provides the best context for living. (Heron 1996)

Provocative indeed. Koolhaas's agenda is to shake the foundations of convention, to incite change, and 'to challenge practices of social reproduction as they are embedded in architectural ideology and spatial programme' (Dovey 2010, p. 103). It is such provocation that is needed to challenge the core of the ideological and epistemological foundations that inform the shaping of urban spaces.

2.4. Access is synonymous with equality

2.4.1. Citizenry

As urban occupiers, we enjoy the successes of our antecedents: their planning and their struggles, their ideas and their creations. We first enter shared urban spaces as children, under the guidance and supervision of adults, gradually learning to choose, navigate, and inhabit them independently. We come to recognise urban form and interpret our place and our movements through and within it. It is in these spaces that urban dwellers are educated in public urban life. Public spaces teach social language and cultural nuance.

> [The city] is a space for encounter, connection, play, learning, difference, surprise, and novelty … The urban involves inhabitants engaging each other in meaningful interactions, interactions through which they overcome their separation, come to learn about each other … these encounters make apparent to each inhabitant their existence in, and dependence on, a web of social connections (Purcell 2014, pp. 149-150).

Purcell's perspective and perception of the lessons learned, and the values derived from public spaces are transparently, neurotypically evaluated. Participation in meaningful interaction, overcoming separation, and

engaging in a 'web of social connections' are socio-cultural reckonings based in the assumption that all people have, are able to have, and desire to have, similar experience. It is reasonable to ask whether the learned social language and cultural nuance is consistent for the 'typical' population, but it is imperative to challenge the opinion that it is consistent for people whose urban experiences are atypical and rarely consulted. Hamraie's (2017, p. 3/127 Chapter 1) description of entering into the public domain confronts the assumption of common experience and the presumption that the urban can engage all people in meaningful interaction:

> When I enter a social space, the electricity of the other, intervening bodies recedes in my presence. Dynamics have shifted, not to accommodate my presence, but to redirect the electricity elsewhere, toward the not-me. There is a certain awkwardness that inheres in rhetorical situations touched by the autistic. A clinical paradigm might locate that awkwardness in my autistic body, identifying the rigidity of my joints, my wayward gaze or monotonic speech, my lumbering body parts that paw their way through public spaces, as if my feet were unaware that objects existed beyond them. Under this framework, my body disrupts rhetorical situations because my body is rhetorically degraded.

Under the framework of normative constructions, Hamraie's body is not accommodated. Other, non-autistic bodies in the same space will be unaware of their direct challenge to her comfort and fit and any atypical autistic 'awkwardness' will disturb the social order of that space. Citizenry is varied and experiences of city publics are many, however, as evidenced in Purcell's analysis, the rhetoric and philosophies that underpin urban design discourse contemplate only the norm of expectation and evaluation.

Urban spaces and the places created within them are publicly presented, communal locations to which we have, we believe, a right of access. The right to *participate* in activities of common ground and the right to *appropriate* space as necessary for that participation underlie the fundamental social rights of citizenry (Lefebvre, Kofman & Lebas 1996). Lefebvre suggests the city belongs to its inhabitants and that simply by virtue of urban habitation, a person is bestowed entitlement to that right (1996; Purcell 2002, p. 105; 2014). The discussion of rights in any context excites political discourse. Lefebvre's much deliberated and debated meaning leads mostly to discourse on what it means to be sociable, and what it means to be sociable within the constructs of privilege, power and politics.

Lefebvre's (2014, p. 149) assertion of rights*,* as interrogated by Purcell in contemporary context, locates the urban inhabitant as a user of space, at odds with urban space as 'exchange value'. Purcell (2014, p. 142) suggests that 'in almost all its forms the right to the city is understood to be a struggle to augment the rights of urban inhabitants against the property rights of owners'. Lefebvre asserts that an urban inhabitant's right to participation and right to appropriation are a fundamental imperative to urban enfranchisement. Purcell (2002, p. 102) argues that this enfranchisement in the current model of 'liberal-democratic citizenship' is provided through the political mechanisms of a place by means of an 'institutionalized voice' … By contrast, the right to the city enfranchises people with respect to all decisions that produce urban space.' Unless those decisions constitute a true representation of all urban inhabitants, however, the production of urban space will result only from normative perspective.

Contemporary actions to enfranchise citizens, as described in the discussion on UN-Habitat and the actions of contemporary urban designers in the previous section, are focused on efforts to return this right to the hands and

minds of the people who occupy urban spaces. Achieving this enfranchisement requires fundamental shift in social, cultural, and political attitudes but also requires an understanding of just how deeply embedded the 'institutionalized voice' is. Dolmage (2018, p. 44) describes this entrenchment in his commentary on Lefebvre in the context of academic ableism:

> Like Henri Lefebvre's claim of a "right to the city", where the mandate of the city as a social construction is to serve all its citizens (and not only an exclusive set), academic ableism leads us to believe that in fact there are some specific bodies and minds that do not have a right to the university. The connected feeling is that the spaces and architecture of the university have been and should continue to be designed to filter out certain bodies and minds.

2.4.2. From public space to shared urban space

Public urban spaces could be described as falling into three categories; (1) ownership and control by public authority (city, municipal, state, national, international), (2) private ownership given over to the public by both formal and informal agreement, and (3) those that fall between the cracks or occupy the periphery, that are neither ordered nor formally intended for public use. The last, the more haphazard, *without-designated-purpose-spaces*, are not questioned in this thesis due to the absence of ratified design intent. This does not mean they are inconsequential spaces. Their less formal, non-designed, non-designated characteristics may for some be qualities of appeal; it is often in these spaces that a city's social outcasts reside.

Public urban spaces of types (1) and (2), developed through themed and guided decision making processes, and correspondingly entrusted with civic responsibility, are central to my discussion. They are the spaces where society actively attempts to define its character, health and strength. They are places that physically manifest a culture's idea of community, and with increasing validity—as the world's populations more readily integrate—they are the spaces charged with the responsibility of providing an arena diverse enough to allow different cultures to come together. Public urban spaces are places designed with an understanding of their role as accommodators of shifting heterogeneous groups. As Watson (2006, p. 1) suggests, public spaces can be identified as being *urban* by their degree of diversity, because, 'living with difference, though always a feature of urban life, is probably now quintessentially what city life is about'.

Within the context of more economically stable *leisure and consumer societies* the quality of public space is deemed synonymous with a city's health and wealth (Gehl 2007). While determiners of quality may hold subjective and regional meanings, they hinge upon the relationship between space and occupier, and can be evaluated by measures of social equity, wellbeing and quality of life. Public spaces are the interstitial life support of urban occupation, providing pathways of access and nodes for activity, as well as places to rest and to gather. In *Life Between Buildings,* Gehl (1987) suggests that city spaces have three key functional purposes—as meeting places, market spaces, and connection spaces—and he asserts that life in these spaces can be divided into necessary, optional, or social activities. Gehl highlights social connectivity and participation as fundamental to quality of life. He suggests that while the 'physical framework [of spaces] does not have a direct influence on the quality, content, and intensity of social contacts, architects and planners can affect the possibilities for meeting, seeing and hearing people' (1987, p. 13).

Amin (2006) casts a more negative shadow on contemporary public spaces and their contribution to the collective wellbeing. Amin argues that the public spaces of today are not the civic spaces of the past (type 1 noted above). Rather, he describes public space as a 'synonym for collective privatism and social antagonism rather than social agonism and civic formation' (2006, p. 8). Public spaces Amin argues, are now varied and disparate, 'plural and distributed', and shaped by national and international media, politics and economics rather than by localised participatory dynamics (Amin 2006, p. 1). A person's social, political and cultural learnings now occur in a multitude of spaces thereby positioning public space as just 'one component, arguably of secondary importance, in a variegated field of civic and political formation' (Amin 2006, p. 1).

By commonly accepted interpretation public spaces are open to all. Ideally envisioned as unrestricted, shared spaces, freely accessible to community members, public places are today recognised as having degrees of restriction (Amin 2006; Sandercock 1997). The public/private spaces of type (2), such as shopping malls and the ground level plazas of office buildings, offer public access with limitations, and instate conditions on behaviour controlled by the private sector. The struggle within urban centres between city public and public/private spaces is political, social and spatial and as the demand for space and land values increase, so do the tensions between acceptable public behaviour and freedom of access and occupation.

Therefore, approaches to the provision and formation of public spaces as civic and communal territory require broader understandings and recognition that public spaces will be measured in terms of the impact they have on the transient citizen. Important also is an understanding that the spaces offered to the transient citizen are mostly created for purposes other than the public

good; corporate and economic agendas dictate form and target specific populations. ‘Increasingly the urban masses are being abandoned to fortune, pushed to the remote and liminal zones of cities and denied the basic rights of urban participation’ (Amin 2006, p. 8). The disenfranchised and the vulnerable remain peripheral and struggle to find their rights of entry. Amin (2006, p. 8) contends that the business of reclaiming or establishing genuine shared space will require ‘sustained effort to improve social well-being and justice’.

What then is the currently accepted definition of public space? Carmona (2010a, 2010b) attempts to unpack contemporary discourse to define a more relevant typology. Using ‘management of public space’ as a criterion for evaluation, Carmona assigns public space discourse into two areas of concern. First, over-managed spaces he describes as those that are ‘increasingly commodified,’ including privatised spaces, spaces of consumption, invented spaces (less authentic, and often themed), and those that restrict access to inclusion through power dynamics. Second, under-managed spaces include neglected spaces, spaces invaded by car use, disabling and parochial spaces that exclude, spaces segregated by design, and ‘suburban living room’ spaces, or, domestic, third and virtual spaces (Carmona 2010b). Carmona concludes with a cyclical argument of cause and effect, maintaining that a pure categorisation of public space is increasingly difficult due to the contemporary practice of intertwining public and private, which results in the ‘homogenization of public space’ (Carmona 2010a, p. 157).

> Urban public space shapes and is shaped by society—its power relationships, priorities and its fears… contemporary urban public spaces have become increasingly contested and fragmented as those within them compete for spatial identities. The argument

> goes that as communication between groups is often misunderstood and differences cannot be resolved, users are willing to accept a homogenized vision of urban public space that neither fosters civility nor community. (Carmona 2010a, p. 158)

This homogenization also operates through the processes of urban design. Because of increased mobility of urban shapers and the rapid exchange of ideas and technological advancement, more generic national and international models replace contextual design approaches. Design processes are standardised by public sector authorities through the creation of universal guidelines and control measures in attempts to regulate or at least influence design agendas. At the same time, Carmona (2010a, p. 159) contends, the mitigation of risk in the 'compensation culture' of contemporary society … 'has led to the creation of safe, but bland and uninspiring public space'.

The objective of urban shapers, therefore, should be a shift from the provision of *public space* and all of its traditional socio-political encumbrances, to a more contemporary, all-inclusive provision of *shared urban space*. With recognition that shared spaces are multiple and varied, and experiences of them complex, the focus for inclusive design requires a shift from a basis of human interactions to one of more holistic consideration.

> It requires for example, starting out with a much more comprehensive audit of the sources of civic ease in public space, an exercise that might reveal how the design and lay-out of mundane intermediaries such as sewage systems, traffic rules, public toilets, street furniture, spaces for dogs, children, cars, pushchairs, affect not only the social experience of space but also the civic remains of such experience. (Amin 2006, p. 7)

2.4.3. Equity and access

The provision of dynamic urban space, as a collective undertaking, can enhance a person's right of access and influence socio-political equity. Without access, Bromfield (2012) advises, people become isolated. Travlou and Ward Thompson (2007, p. xvii) contend that 'inclusive access to high-quality public spaces is a cornerstone of democracy and social equity, a fundamental condition for social and political participation, and a key element with potential to enhance wellbeing and quality of life'. Urban designers actively and intentionally shape the physical and social connections to and within space. These connections both reflect and construct the life-blood of community. Connectedness—in terms of neurotypically described physical and perceptual links—allows people to understand and navigate environments. It is such connections—the sharing of language, concepts and understanding—that allow for, and provide access to, a city's social and cultural environments.

The call for equitable and inclusive access to all forms of space comes from many voices. Diverse populations have pursued recognition and continue the push to be heard. Marginalised groups such as women, racial minorities, queer communities, people with disabilities, and youth, persevere with efforts to be recognised and included. The depth of 'othering' has compelled formalisation of these actions into movements to expose truths, to challenge prejudices, and to apprise the norm of the extent of systemic marginalisation of diverse populations. Engagement with diversity is therefore key to exposure and hopefully to positive change, and the key to engagement is the dismantling of 'othering.' Determining how to engage and breaking the traditions of engagement that are heavily entrenched in the power

relationships of difference, must come from sharing language, concepts, and understandings and by creating new ways to communicate.

Feminist theory, queer theory, and the transformative paradigm for example, have forced movement. Massey (1994) detailed the depth and impact of gendered social and spatial relations on the formation of spaces and places. Massey's influential work not only interrogated the impact that gendered power has on the development of space—'in a myriad different ways, which vary between cultures and over time'—but how development 'both reflects *and has effects back on* the ways in which gender is constructed and understood in the societies in which we live' (p.186). In effect, both action and inaction perpetuate and reinforce constructions of power. The breakdown of the traditions of ableism, therefore, must be a holistic and epistemic undertaking. Hesse-Biber and Griffin (2015, p. 72) state, 'Feminist thinking and practice requires taking steps from the "margins to the center" while eliminating boundaries that privilege dominant forms of knowledge-building, boundaries that mark who can be a knower and what can be known'.

Tauke, Smith and Davis (2015, p. 3) contend that designers need to engage in this knowledge building process to achieve better outcomes for diverse populations; 'designers can no longer exclusively design in their own image … Designers must actively consider the perspectives of "the other" in both general and specific terms'. Yergeau (2018, p. 9/80 Introduction) articulates this imperative; 'what we do not know, and what we often purposively ignore, are autistic narrations of such rhetorical events, the interbodily potentials, desires, and moments that structure an autistic life, or any life. To whom do we listen? The autistic or the nonautistic?' It is only this direct rhetorical process that will propel improvement in the arena of equity and access. Equal access to public spaces is only minimally addressed in the policies and

practices of contemporary urban design, through the concepts of *Inclusive* and *Universal Design*.

Universal Design (UD), as a formally recognised practice, has its roots in the 1970s in the United States. Civil rights movements—discussed in chapter 1—demanded debate on equality and importantly lay bare and gave voice to victims of social and institutional practices of discrimination. Alongside the racial activism of the 60s and 70s there grew a drive to recognise, and to advance the rights of people with disabilities. Post-war attempts to integrate disabled veterans back into 'normal' life, and specifically, efforts to improve access on and within university campuses were the impetus. *Barrier-free design*—or *disability rights*—movements advanced, and after decades of action to raise awareness of social, institutional and political inequities, the United States formalised legal provision for access. The US government enacted 'laws prohibiting discrimination against people with disabilities and provided access to education, places of public accommodation, telecommunications and transportation' (Story, Mueller & Mace 1998, p. 7). The *Americans with Disabilities Act (ADA, 1990)* provided the legal backbone for a new social awakening. The ADA, implemented under Accessibility Guidelines (ADAAG), are credited with greatly increasing public awareness (Preiser 2008). What was also significant about the ADAAG was the broadening of the scope and definition of 'access' from a purely structural application to include services and programs, and for the first time, attitudinal and social behaviours were identified as a barrier.

Disability rights activism continued spurred by dissatisfaction with the scope of understanding, limited application, inconsistencies in implementation of standards, and with the application of policy. Elevated by the increased participation of self-advocates, these grievances gave rise to the formation of—what was intended to be—a more universally designed standard of

guidance. Ronald Mace coined the term 'Universal Design' and in 1989 founded the *Center for Universal Design* at the College of Design, North Carolina State University. Universal Design was conceived as a broader and, in intent, more holistic concept. The principles of Universal Design were expressly aimed at human diversity. They promoted acknowledgement of the spectrum of human abilities and recognition that variation in ability may occur with 'age, disability, the environment, or the circumstances', not only with conditions of life-long bodily impairment (Story, Mueller & Mace 1998). Universal Design provided the foundations for a paradigm shift. It was an attempt to alter the conceptions of the able majority and a call for designers to consider the entire life span of the users of the spaces and the products they were designing.

In the United States construction industry accessibility standards became enforceable as the *2010 ADA Standards for Accessible Design* for all new construction and alteration works (United States Department of Justice 2010). Similar movements, Acts, and standards were adopted worldwide and the principles of Universal Design today underlie international understandings of approach across a wide range of disciplines. Preiser (2008, p. 79) suggests that the intended scope of Universal Design goes beyond the original premise of access to buildings, 'beyond minimum dimensional and other requirements of the built environment and is pertinent to the entire life space of populations'. Focusing on its more political stimulus, Imrie (2012, p. 874) proposes that the 'overarching principle of UD is avoidance of discriminatory design':

> For disabled people, UD is, potentially, a challenge to the disabling values and attitudes of society by designing products and places that are accessible without requiring the use of assistive or specialized techniques and technologies. It is

> premised on assuring disabled people's integration into society by reducing and seeking to eliminate discrimination by design and ensuring that this occurs in ways whereby attention is not drawn to a person's impairment that, otherwise, might be a target of/for pejorative attitudes and stigmatization.

The intent, philosophy, and subsequent codification of Universal Design into policy and guidelines contribute to the humanitarian principles endorsed by the United Nations and the World Health Organization. In Australia the Disability Discrimination Act 1992 (DDA) attempts to eliminate discrimination and provide rights of equality for individuals with a disability (Government 1992). Disability is clearly defined in this document, first as 'a total or partial loss of the person's bodily or mental function.' It then incorporates several more specific qualifications including one that could be construed as being applicable to autism:

> (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour (*Disability Discrimination Act 1992* (Cwth), p. 5)

The medicalised language and ableist positioning used in these directives is clearly problematic. Words such as 'loss' to describe neurological difference and 'disorder,' 'illness,' 'disease,' 'affect' and 'disturbed' all reinforce the 'otherness' discussed in chapter 1. Importantly, these edicts are the instruments that inform policy and instruct the guidelines used by urban shapers. In an Australian context, urban designers, architects, planners, builders, and others, encounter the DDA in the National Construction Code (NCC) and discipline-specific standards. The NCC 'sets the minimum requirements for design, construction and performance of buildings

throughout Australia' (Australian Building Codes Board 2016). It refers designers to the *Disability (Access to Premises – Buildings) Standards 2010,* and the *AS1428 2010 Design for Access and Mobility* set of Standards, which provide more detailed guidance for built environment professionals.

These guidelines, however, remain specific to building access and occupation. The Standards encompass a considerably narrower definition of disability than that outlined in the DDA. Specifically, the Standards provide for access for individuals with atypical physical characteristics related to sight, mobility, and hearing. They do not address access for persons with atypical cognitive or sensory faculty. Notably there is divergence from the intent of the Act, and from its function as guarantor of equal access through the provision of all-encompassing codes of practice. Thus, not only is there reinforcement of otherness from guiding directives, there is narrowing and dilution of intent.

Similar critiques of performance occur outside of Australia. Imrie (2004a) describes the provisions of Part M of the United Kingdom's building regulations as being responsible for the reduction of the idea of accessibility and design quality for disabled people to 'a specific form (or norm) of impairment … and to achieving the technical dimensions … relating to an inanimate object (that is, a wheelchair)':

> The physical and technical discourses of Part M are, therefore, likely to encourage architects to design for a category of corporeal substance (i.e. the impaired body) in ways that reduce corporeal complexity to a "type" (i.e. the wheelchair user). This type, like others, conceives of building users, such as disabled people, as either non-existent or revolving around an "identikit" in which technical categories, often bereft of human or social ascriptions, are deployed as the basis of design.

(2004a, p. 3)

Williamson (2012), discussing the field of industrial design, suggests that the combination of political agenda for inclusion with the products that market inclusion, causes a Universal Design paradox. Williamson notes that the politics surrounding social inclusion and Universal Design ‘offered the possibility of creatively inspired, socially progressive design that was also marketable’ (2012, p. 235). This marketing of product, or the commercialization of Universal Design into successful consumer products, contributes to the divergence of the practices of access and inclusion, away from the overarching intent of the principle. The translation of idea into reality, or principle into practice, is where the divergence begins.

Interpreting the philosophies and intents of Universal Design, and the agendas set forth in political declarations, strikes difficult ground when attempts are made to codify the ideology into practical guidance.

> While the disability rights movement may have won legislative battles culminating in federal disability rights laws [in the United States], it did not directly propose strategies for challenging the professional practices through which the design professions had adopted the normate as an ideal type. Efforts to educate designers and challenge professional practices by UD advocates can be understood as a parallel movement to the direct action and legislative demands of the disability rights movement.
> (Hamraie 2012, p. 4)

Converting intent into directives that can be effectively implemented by practitioners is challenging. Furthermore, when directives are transcribed into instructions for application to the built environment there is risk of

further dilution. The arms-length nature of the practice increases the likelihood of preference being given to concepts that are more easily implemented. The result is a simplification and narrowing of the definition and understandings of disability, and convenient interpretations of those understandings into more marketable measures and products. Williamson's criticism of current industrial design practice is equally applicable to the processes that provision the built environment. The commercial success of Universal Design, its seamless integration into products and standardized form enthusiastically consumed on the mass-market, 'could amount to hiding or ignoring actual people with disabilities' (Williamson 2012, p. 235).

Attempts to extend the parameters of inclusion beyond design technology solutions have driven similar progressive approaches and advices among consultants and lobbyists. The term and concept of Inclusive Design has evolved alongside Universal Design, primarily in Western Europe. Inclusive Design emphasizes the development of integrated design solutions and practices. In the United Kingdom, Inclusive Design principles have been incorporated into policy, attempting to enforce similar ideas of universality and inclusivity. In 2008, the UK government's advisor on architecture, urban design and public space, the Commission for Architecture and the Built Environment (CABE), provided a briefing entitled, *Inclusion by design: Equality, diversity and the built environment*. The document acknowledged the preceding decades of improvement of accessibility to and within the built environment, but stated that 'social, cultural and economic inequalities are still being literally built into new places, and [that] planners and designers need to examine more closely the impact of their decisions' (Commission for Architecture and the Built Environment 2008, p. 3). Importantly, CABE explicitly broadened the definition of inclusion beyond ideas of access, to include social, cultural and economic dimensions, and significantly, it recognised differentials in experiences of the built environment (2008, p. 4).

Incorporated into the UK Design Council, CABE advanced the notion of inclusion as multifaceted, providing advice and strategies for physical, visual, social, auditory, demographic and cognitive inclusion (Design Council 2015).

Differences between the concepts of Universal Design and Inclusive Design could be arguably semantic. Their ideals lie in the notion of universal inclusivity and their current philosophies recognise and incorporate broader social, cultural and experiential parameters. Organisations and advisory bodies charged with the responsibility of informing policy and legislation on equality and inclusive practices have advanced dialogue but the translation and filtration into majority practice remains limited. Imrie (2012) suggests that the impediments to a more holistic translation lie in the problem-solving approach that continues to permeate design practices. Problem solving demands a design solution response, and like Williamson, Imrie argues that this response has resulted in the marketization of 'access as the primary means to ensure the accessibility of products, including the built environment.' Thus the core philosophical notion of the 'right to access' has been reduced to 'a right to be exercised through a market presence or transaction' (2012, p. 873). This process, Imrie (2012, p. 877) argues, has contributed to the 'institutionalization' of Universal Design:

> The development of UD is part of a broader social and political movement characterized by transnational networks, including scientific interactions and exchanges between professionals from academia, government and business. These networks are part of the institutionalization of UD, in which its value-rationality and legitimacy are shaped, and policies and programmes to propagate its principles are developed and enacted.

The recognition of the need for, and the justice in, the adoption and application of fully integrated 'design for all' practice exists but as Imrie recommends (2012, p. 873), both Universal and Inclusive Design provide only partial understanding of how to address the relationships between disability, equality, access and design. In the context of the design solution approach to an inclusive built-environment, Universal Design has become a placebo that allows technological answers to a socio-political issue. As Titchkosky (2011, pp. 23-24) states, 'the existence of a universal sign for access is reliant on an exclusive and exclusionary physical and social environment. In order for a sign to point towards access, there must be an assumption of a general lack of access … [it] signifies the normalcy of inaccessibility.' It is necessary therefore to continue to expose diversity of experience of the built environment to increase awareness of the shortfall of contemporary practice and the persistent barriers to social and spatial inclusion.

From this perspective, it is the codes of practice and the standardized guidelines that allow designers to escape comprehensive understandings of 'actual people with disabilities.' There is institutionalized enabling of practices that remain discriminatory, perpetuating difficulties of access for a significant percentage of the population. The opposing perspective, or suggestion that a lessening of regulation might be a more successful means of avoiding discrimination, is an equally unsatisfactory proposal. In his book, *The social life of small urban spaces*, Whyte (1980, p. 30) argues that a 'Lack of guidelines does not give builders and architects more freedom. It reinforces convention.' Without political will and regulated guidance, normalised attitude and practice is perpetuated. The provision of unhindered access to places without the need for 'assistive or specialized techniques and technologies,' and the elimination of 'pejorative attitudes and stigmatization' needs to be realised before there can be any claim to the provision of built environment equality.

2.4.4. Spaces and places

Social and political activism, laden with philosophies of equity and social justice, has invigorated thought, spurred new approaches to design and demanded that inequity in cities be addressed. A person's right to inhabit a public space is a notion unlikely to be challenged within the liberal-democratic purview but, that right may be consistently challenged on the ground, by means of socio-political dogma. Public spaces are governed by socio-political rules, and it is the tenet of the rules of transformation that determines the character of the conversion from public *space* to public *place*. As defined in the Introduction, *space* is determined by location, physical and material dimension, and time. *Place* extends the definition of space to incorporate meanings, meanings that are both installed by the creators and interpreted through the experience of the user. Dovey (2007, p. 1) describes the powerful position of the designer of *places* in the following passage:

> Architecture and urban design 'frames' space, both literally and discursively. In the literal sense everyday life 'takes place' within clusters of rooms, buildings, streets and cities we inhabit. Action is structured and shaped by streets, walls, doors and windows; it is framed by the decisions of designers. As a form of discourse, built form constructs and frames meanings. Places tell us stories; we read them as spatial text.

The stories a place provides for us require interpretation, and it is at this nexus, this very moment in time and space, where the themes of the story may become lost in translation. If the equipment the interpreter has available to them differs from the equipment that the designer thought they would have, there is a high risk that the storyline is misunderstood. Discourse

addressing these differences is examined in Chapter 3. The point I make here is that it is the political and social genealogy of place that holds the invisible power of inequity.

It is easy to conjure images of physical spaces that provide and conversely, deny access. Discussion in the previous section evidences attempts to overcome equality of access through top-down intervention. However, it is this same intervention that, ironically and unfortunately, can insert inequity. The marketing of product described by Williamson, the 'identikit' response to the provision of accessibility described by Imrie, the 'institutionalized voice' described by Purcell, and the political and economic agendas of developers and governments described in the UN-Habitat report, contribute to the formation of public places that have pre-determined meaning and inherent behavioural expectation. Public spaces are easily created with or transformed into places intended to manipulate behaviour. Through practices of avoiding disturbed or of disturbing behaviour, 'the built environment mediates, constructs and reproduces power relations. The ambiguities of 'framing' reflect those of the nexus between place and practices of power' (Dovey 2007, p. 1).

Cahill (1987, p. 312) asserts that the rules of public places are ceremonial, that there exists ceremonial expectations and ceremonial conduct, ceremonial deviance, order, responsibility, routines, responses and expectations, all of which derive from the governing 'religion of civility'. This religion Cahill (ibid) contends, provides 'contemporary civil society with its distinctive moral shape.' Children are socialised into this religion; he asserts,

> If our contemporary civil society is to retain its distinctive moral shape, then successive generations of initiates into that society must be mobilized as self-regulating performers of the

> constituent interpersonal rituals of our religion of civility. That requires that they do somewhat more than simply learn the code of ceremonial conduct which we commonly call etiquette. In a sense, they must have certain elements of behaviour "built into them" (1987, p. 313).

Deviation from the rules, through 'unconventional behaviour' therefore 'threatens disorder' (Ryan 2005, p. 291). The requirement for conformity is a determinant of how spaces are used, and by whom. Ryan's (ibid) research into *learning disabled children in public places* revealed a tension between 'nonconformity and the significance to most people of reliable, legible and predictable practices in public spaces. The ongoing right of access, Ryan asserts, is afforded to those who learn how to obey the rules. The rule breakers therefore, will experience varying degrees of social discomfort.

2.5 Difference is fundamental to the spectrum of normal

2.5.1. Semantics and semiotics

The built environment has been ostensibly addressed in terms of its relationship with the less able-bodied. While genuine attempts to erase inequalities have provided some measure of improved bodily access to the built environment, Bigby and Wiesel (2011) propose that those with an intellectual disability have not been afforded improved access because of the narrow interpretation and generic approach to what it means to be disabled. They contend that discriminatory actions occur as a result of narrow understandings and because of instituted and stigmatised perceptions of disability. Physical and social *ability* and the state of being *normal* are value laden. At the crux of the stigma is language that subliminally reinforces and

perpetuates adverse socio-cultural perceptions—the language used to describe what Sinclair termed a *different way of being*. The words disability and disabled, normal and abnormal are fundamentally problematic. They carry with them established societal standards, standards that are lesser or deficient implying reduced status. This negative emphasis does not assist in enlightening the everyday attitudes and actions of a population. 'We live in a world where individual mobility, autonomy and personal competence are both highly valued and seen as normal. People who are less than fully mobile, are interdependent with others, or seem 'slow' then become the problem' (Boys 2014, p. 21).

As described in chapter 1, individuals with autism are diagnosed via the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association 2013b)*. Discussion in that chapter evidences varied opinion on the accuracy, appropriateness, and impacts of clinical diagnoses. Successive editions of this manual have altered definitional understandings and terminology, but all retain the view of a person of reduced capacity and competency, as is evidenced by the term 'disorder' retained in the nomenclature.

> Autism is variously viewed as a psychiatric condition, a disorder, a disability, and a handicap. Ever since Kanner's (1943) description of the aloneness of these children, psychiatry has labelled and categorized them as abnormal, ill, and deficient…we have had a single view of Autism thrust upon us: an essentially negative view in which children or adults with autism are characterized as "impaired". (2002, p. 186)

Baron-Cohen states that it is possible and plausible to separate 'Asperger Syndrome (AS)' from 'Autism Spectrum Disorder' and label it as a *difference*,

leaving autism as a low function (LF) *disability*. Definitional criteria describes an individual that has both autism with ‘an IQ in the normal range (or above)’ and a ‘communicative abnormality / history of language delay’ as having Asperger Syndrome (2002, p. 186). Baron-Cohen (2002, pp. 186-187) posits that this higher functioning (HF) autism challenges any diagnosis of disability and contends that a ‘nonjudgemental’ analysis of differences using DSM-5 ‘diagnostic features’ makes it ‘possible to describe AS in value-free ways’; it is only because we are part of ‘a world where individuals are all expected to be social, people with AS are seen as disabled’ (Baron-Cohen 2002, p. 189). However, Baron-Cohen advises that while it is possible to eliminate a clinical diagnosis of Asperger’s, it may not be in the best interest of people to do so; ‘*disability* may need to be retained for AS, as long as the legal framework provides financial and other support only for individuals with a disability’ (Baron-Cohen 2002, p. 186).

Critics of the HF/LF division describe the divisiveness that permeates such diagnostic debates. As well as the deficit view and binary approaches to autism diagnoses generally, this particular binary causes rifts and fosters stigma. ‘Among autistic activists there is growing resistance to the clinical and everyday use of “functioning labels.” They are seen as tools of bigotry used against those labelled as “low functioning,” and a way to deny services and accommodations to those labelled as “high functioning.”’ (Thomas & Boellstorff 2017, p. 14). It is important to note that it is these instituted stigmatised perceptions of disability that form the basis of current socio-medical support systems. Such labels fuel and sustain us-them stereotyping.

In the case of autism, APA definitions provide the clinical framework around which assistance can be both formulated and derived. This position presents a Catch-22 situation for people who find themselves outside of society’s definition of normal. With social, cultural, medical, and built environment

structures based upon an able-bodied, able-minded stereotype, the facility for those who do not fit the type will only be provided if a person accepts and wears the appropriate *ability label*. If a person chooses to reject their socially and medically determined label, they will likely have difficulty gaining access. Without the shift proposed by Sinclair, and advanced by Chouinard (1997; Chouinard & Crooks 2003) and others (discussed in the next section), the Catch-22 will remain. The continued and accepted use of words that devalue a person's social standing are a recognisable testament to ableism. Even with progressive agenda and processes, the language used has sufficient power to perpetuate discriminatory practices.

2.5.2. Difference and ableism

Scholarship on the geographies of disability is growing in strength. Investigations in this area are now more specifically addressing the marginalisation of people who do not fit the stereotype of *normal* due to the power constructs of public spaces (Wiesel 2009; Wiesel, Bigby & Carling-Jenkins 2013). The concepts of the environment as enabler, and of the built environment as disabling, have impelled broader and more in-depth discussion. Sinclair's 1993 plea is slowly infiltrating discourse.

Chouinard (1997) contends that people have a duty to shift the idea of 'difference' to a place within the normal range of human experience rather than considering it to be wonton of correction. By the late 90s it was well recognised that perceptions of, and conformity to, normality enabled discriminatory actions and disabling environments. Chouinard and Crooks (2003, p. 385), speaking of 'spaces of oppression and intolerance' recommended challenging ableness in small measures to complete the shift, and, in sync with disability advocates generally, stressed the importance of giving voice to those who have lived and intimate knowledge. What was being

submitted was advice that the semantics and semiotics of *normal* and *difference* were the real obstructions to equality. A shift in the emphasis from 'doing things normally' to the 'normality of doing things differently' was proffered as a refrain to inform the politics around traditional accommodations of disability (Hansen & Philo 2007, p. 493). Davidson (2010) concurs with Hansen and Philo stressing that the key to removing or to minimising barriers built into the environment is in alteration of the 'thinking' that governs disability access and accommodation. By shifting the focus from thinking 'about' disability, to one that encourages thinking 'with' disability, barriers will be more easily understood and appropriately addressed.

Hansen and Philo (2007, p. 499) submit that because 'non-disabled authorities' have largely determined the bases of policy and guidelines for access, there exists a misunderstanding of needs and a resulting lack of effective accommodation. This fundamental flaw forms part of the ableist dynamic. The result, Hansen and Philo argue, is both a tokenistic and '(far from tokenistic) approach that strives to "correct" the disabled body, to produce corrected bodies that fit in with the existing shapes and expectations of non-disabled space' (Hansen & Philo 2007, p. 500). Nothing is done to bridge the divide of understanding that exists at the inception of the action. Dolmage (2018, p. 70) suggests that this divide exists because, 'Disablism can never be fully disconnected from ableism … The disablism built into that overarching desire for able-bodiedness and able-mindedness comes from the belief that disability should not and cannot be something that is positively claimed and lived within.'

Imrie's several papers on the subject of ableist geographies are themed with a critique of ableist sociology (1996, 2001, 2004b; Imrie & Thomas 2008). Imrie's (2001, p. 231) writings track the concept of *ableism* through social,

socio-spatial, political and professional paradigms, arguing that ‘geographers and scholars of urban studies ought to develop a more active interest in the diverse and multiple geographies of disability’. Imrie specifically speaks to policy makers and architects in his quest to educate his readers.

> This, then, is a call for an architecture that recognises, and responds to, the diversity of bodily needs in the built environment by (re)producing a fluid form that will affirm ambivalence and irony (rather than seeking to reproduce a static, singular, conception of the body). A reflexive architecture is required which is ‘open-minded', without boundaries or borders, and sensitised to the corporealities of the body. An important component of this is for architects to identify the multiplicity of corporeal or postural schemata of the body. (2003a, p. 64)

Thus, exhibiting ‘difference’ is now recognised as an attribute that needs to be shifted from social and cultural perceptions of being ‘unable’ into the terrain of being a fundamental part of the spectrum of ‘able.’ Colloquial and academic understandings, reinforced by medical positioning, can effectively remove barriers by redefining what it is to be normal. The notion of normalising difference, however, if not addressed from the correct viewpoint and pursued with the correct intent, can in fact reinforce prejudice. Normalising difference is not about changing those perceived to be abnormal by correcting differences; it is an undertaking for those deemed to be normal. It is about changing societal perceptions of difference. The principle of ‘normalization’ advanced by Wolfensberger (1982, p. 138) advocates for education of the able:

> Normalization is concerned with the identification of the unconscious, and usually negative, dynamics within human

> services that contribute to the devaluation and oppression of certain groups of people in a society, and with providing conscious strategies for remediating the devalued social status of such people.

Wolfensberger's (1982, pp. 134-135) objective was 'social role enhancement' … 'a means of preventing, minimizing, or reversing societal devaluation'. He advocated normalization strategies for persons considered to be of lesser value. By reducing or preventing the perceptions and values that define difference and cause devaluation in the eyes of observers, Wolfensberger contended that unfavoured characteristics would be redefined and people would attain more valued social positions.

This Normalization Principle provided a much needed and refreshing perspective to social and psychological methods of care and assistance for individuals with disabilities. Rather than being viewed as people whose differences require correction, this new focus would afford individuals greater respect as valued members of the community. Wolfensberger's Principle, along with *Social Role Valorization* and the notion of the *Dignity of Risk,* gained worldwide recognition and was adopted—predominantly in the United States and Canada—into many government and private sector care programs (Disability Practice Institute 2014). Social Role Valorization is premised on 'enabling, establishing, enhancing, maintaining and defending valued social roles' (Disability Services Australia 2014, p. 2). Dignity of Risk seeks respect for each 'individual's autonomy and self-determination (or "dignity") to make choices for himself or herself' (Disability Practice Institute 2014, p. 2).

These philosophies have, through filtration, driven policy and influenced disabled service provisions. They continue to evolve and to enlighten responsible socio-medical practices, however they have progressed only

marginally beyond this domain. Dissemination of these values into the broader social conscience, and interpretation into more practical applications, is slow and challenged on many other contextual fronts. Critiques by Titchkosky (2011), Hamraie (2017), and Dolmage (2005) for example, suggest that the practice of normalising differences turns focus away from addressing the specific needs of people who are forced to function within environments that do not recognise their bodies.

2.5.3. Self-advocacy

Efforts to educate and enlighten have been strengthened by those such as Jim Sinclair, and voices of experience have confronted conservative attitudes and contested ignorant social policy. Increased self-advocacy, working both concurrently and consequently to policy and agenda, has gnawed at the collective social conscience. A primary enabler of and boon to self-advocacy has been, and continues to be, the explosion of the Internet and the almost ubiquitous access to personal computers. 'In July 2010, entering the term "autism" into the Google search box resulted in more than 19 million hits in 0.21 seconds' (D'Auria 2010, p. e11). In July 2017, the same entry returned 117,000,000 results in 0.63 seconds and a search of the term "autism blog" returned 23,600,000 results in 0.50 seconds. While it is not the intention here to suggest that all resulting entries provide valuable, useful, positive, or even accurate information, what is significant is the indiscriminate accessibility and availability of information.

Access to the Internet is not subject to the same socio-cultural rules of engagement required for successful navigation of external public spaces. Successful computer-based cybernetic interaction can be independent and unidirectional, or, by personal choice, it can be shared and communal. Importantly, computer use, and Internet navigation are socially acceptable as

either individual or private activity. They neither demand nor expect direct person-to-person connection. Cyber-space is one place where predominant interpretations and judgments of *different* and *normal* are obscured or simply not evident. Individuals who do not subscribe to, or have difficulty navigating the dominant social etiquette and language of public spaces, can be socially successful and active online community members. Consequently, the 'web provides a very accessible mode of information, support and even friendships for individuals living on the autism spectrum and their families (D'Auria 2010, p. e11).

Davidson (2008, p. 791) states that the 'Internet is shown to be an appropriate, accommodating medium for those on the spectrum, given characteristic preferences for communication at a socio-spatial distance'. It provides a safe place, one without requirement for physical and neurological navigation or occupation of geographic social spaces. The evolution of online autism-specific communities therefore was a natural progression.

> Here people with autism can traverse geographical boundaries and interact with 'like-minded' others. It is in these online communities that people with autism can become the majority rather than the 'othered' minority, and therefore interactions between individuals can take place in an autism-friendly environment. Equally, these environments provide an opportunity to interact with neurologically typical individuals, without the complexities of non-verbal cues to negotiate in exchanges (Bertilsdotter, Brownlow & O'Dell 2013, p. 368).

The cybernetics of the medium is also suggested to be particularly enabling for individuals on the autism spectrum. By design, the functional and interactive systems of the Internet and of computers themselves favour visual

learners; a trait commonly attributed to people with autism (D'Auria 2010; Grandin 2006a; Grandin 2009b). 'The value of technology is that it uses visual clues to enhance understanding by combining activities with listening and auditory skills' (D'Auria 2010, p. e12). Direct verbal instruction and group-based interaction, like that of a traditional classroom, are substituted with graphic presentation by numerically driven machinery.

Silberman (2015) attributes his quest to understand autism, in his book *Neurotribes,* and the impetus for his article, *The Geek Syndrome* (2001), to an encounter with a cruise ship full of computer programmers. Covering a shipboard convention in 2000 called the 'Geek Cruise', Silberman, a journalist, entered into the world-space of a technologically-minded group of people he later described as, 'a tribe of digital natives with their own history, rituals, ethics, forms of play, and oral lore (2015, p. 3). The arena of digital technology, Silberman (2015, p. 3) suggests, is a 'convivial society of loners', providing sanctuary for the 'kids formerly ridiculed as nerds and brainiacs', and an enabler constantly propelling them to become 'the architects of our future':

> Their medieval predecessors might have spent their days copying manuscripts, keeping musical instruments in tune, weaving, or trying to transmute base metals into gold. Their equivalents in the mid-twentieth century aimed telescopes at the stars, built radios from mail-order kits, or blew up beakers in the garage. In the past forty years, some members of this tribe have migrated from the margins of society to the mainstream and currently work at companies with names like Facebook, Apple, and Google.

It is not surprising therefore that technological cybernetics facilitates autism connectivity. The purported *Silicon Valley epidemic* is itself the accelerant of

the invention (Silberman 2015, p. 5).

A further and significant advantage to interactions in online spaces is the allowance for, and tolerance of, diversity and differences within the user group itself. Unlike public encounters where a person is exposed to pre-judgment, characteristic labelling, and placement into the singular social group of 'other,' online interaction provides opportunity for individual identity. Although there exists an online 'autism community,' membership to it is at the discretion of the individual. Online communities are dynamic, increasing (as evidenced in the autism blog statistic above), and play a central and vital role in the process of giving voice (Davidson 2008, p. 802). Both collective and independent advocacy, either intentionally or inadvertently communicated, has increased accessibility to information and awareness for people with and without autism. The Washington DC based Autistic Self Advocacy Network (ASAN), evidences a powerful contemporary sentiment. With chapters in Canada, Australia, Israel and the United Kingdom, ASAN (2017) vigorously promote their motto, 'Nothing about us without us', and describe their 2006 founding as follows:

> in response to the lack of representation of autistic voices in the national dialogue on autism … started by autistic adults who were unhappy with the prevailing public dialogue on autism, believing that the autism world would be better served by ending the misguided search for a "cure" and focusing on empowering and supporting autistic people and all people with disabilities to live the lives we wanted.

Individual self-advocates, such as Temple Grandin and Jim Sinclair, plus a host of both unintentional and deliberate protagonists, have assisted in re-educating orthodox understandings. Online blogs, forums and organisational

websites have demonstrated that an alternative way of being is not a disabled way of being until people or environments determine that it is. Online self-advocacy has proven that autism is a spectrum and that there is diversity within the diagnosis. The World Wide Web has become an acute mechanism for awareness that reaches a wider audience than any conventional, more formalized, more neurotypically-determined means.

Stories and images that circulate the Web have the ability to work on an emotive level. They resonate, such as the websites and YouTube videos of non-verbal Carly Fleischmann (2012; 2013) who at the age of 11 began to communicate by typing and now has her own website and blog, and the Laser Beak Man artwork and stories created by Tim Sharp (2017) that literally illustrate 'his original way of looking at life', which have expanded into a published book, a television series, theatre production and online sales of associated paraphernalia. Autism Network International (ANI), coordinated by Jim Sinclair, describes itself as 'an autistic-run self-help and advocacy organization for autistic people', stating that the 'best advocates for autistic people are autistic people themselves' (Sinclair, Bordner & Shelly 2011). The courage and strength needed to contest stereotypical and neurotypical understandings of autism and of difference is more easily facilitated and ever-present in this forum. It provides a place from where mainstream attitudes and misconceptions can be safely and more thoroughly challenged, a 'collective voice and 'movement', one that contests predominant constructions of AS [and autistic] difference as disorder or disability' (Davidson 2008, p. 802).

The Internet, and the ever-increasing access to it, has expanded comment, opinion, and contribution to everything in contemporary life including the built environment. Ellard (2015, p. 13) states, 'Now, perhaps more than ever before, engaged citizens of the world are keen to understand how place works

and even to contribute to the work of building better places'. Participation in this process by online 'autism communities' (D'Auria 2010; Davidson 2008) is now possible because of the 'new tools that are available for us to connect with one another, share ideas, images, and even aspects of our inner mental and physiological states' (Ellard 2015, p. 13).

2.5.4. Labels

It is Sinclair's *Autism Network International* that Silberman credits with the origin of the term *neurotypical* (2015). Silberman writes that Tisoncik, a member of the group, 'turned the diagnostic gaze back on the psychiatric establishment' inventing the label *neurotypical* as a sarcastic gesture to describe a 'neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity' for which there was 'no known cure' (2015, p. 441). The term itself was intended by ANI to be provocative, a poke at established attitudes and by default, established approaches to formalized care and assistance. Ironically, it became instead an ableist prop. The term *neurotypical* is now widely adopted and used to identify people whose cognitive processes are typical.

Categorizing people into groups can be argued as a necessary part of the endeavor to un-group the same individuals—recall Hamraie's (2017) discussion on crip theory. Once a group is defined, its needs can be evaluated, and appropriate actions taken. For every defined group there exist one or more counter groups that provide measurable standards. Labels given to groups, and their associated defining characteristics, progressively lose favour or are proven incorrect, then redefined and changed. *Thinking differently*—contrarily defined by typical and neurotypical, diverse and neurodiverse—is a contemporary attempt to minimize *othering*. It is a label devised to divert discriminatory attitudes. Describing a person as *neurodiverse*

is another attempt to remove implications of abnormality and of the need for correction. Jaarsma and Welin (2012, p. 1) state that 'the concept of neurodiversity regards atypical neurological development as a normal human difference'. Silberman (2015, p. 16) states that the term neurodiversity provides a 'notion that conditions such as autism, dyslexia, and attention-deficit/hyperactivity disorder (ADHD) should be regarded as naturally occurring cognitive variations with distinctive strengths that have contributed to the evolution of technology and culture rather than mere checklists of deficits and dysfunctions'. It is a term of salutogenic intent that expands the spectrum across the general populous. As previously discussed, this naturalising of differences can also have the unintended consequence of shifting focus away from specific needs and effective attention.

2.6. Diversity discourse

2.6.1 Social justice

Paradoxically, the key to connectedness is the recognition of diversity. A shift in perspective reasons that it is not about determining what people have in common and providing linkages based upon their commonalities, rather, it is about recognising diversity and providing places where variations in ability can be comfortable. 'We live in a world where individual mobility, autonomy and personal competence are both highly valued and seen as normal' (Boys 2014, p. 21). This etiology nurtures the ableism upon which approaches to inclusive design are based. Change therefore is required at the starting point. 'This requires seeing disability and ability as a series of overlapping concepts and experiences, with varying and differential effects that are ambiguous and relational' (Boys 2014, p. 22).

Diversity discourse itself has a shifting history. Being neurodiverse rather than having a disorder is part of the process Boys describes as ‘re-framing disability’ (2014, p. 20) but the true integration of diversity and the understanding of what diversity is, continue to be debated. Michaels (2016, p. 5) states, ‘our commitment to diversity has redefined the opposition to discrimination as the appreciation (rather than the elimination) of difference’. Difference has therefore become once again, a focus. Because of more politically conservative and economically driven climates, the socially inclusive actions and programs that rose out of the 1960s and 1970s have shifted to an alternative model that centres on the celebration of difference. Tauke, Smith and Davis (2015, p. 4) claim that in the United States, this conservatism has changed the ‘model of inclusion’ to a narrower focus that has ‘elevated individual achievements over the amelioration of institutional barriers’. Diversity now conjures images of racially mixed and ability mixed groups of people, a tokenistic collection, ‘a static list of characteristics’ (Tauke, Smith & Davis 2015, p. 4). Michaels (2016, p. 6) asserts that the *trouble with diversity* is that in contemporary society it has become an economic argument ‘where the differences between us present a problem: the need to get rid of inequality or to justify it’. It is far simpler and more palatable, he suggests, to celebrate diversity though selecting the differences we can appreciate, and ignoring the ones we can’t.

To progress discourse on diversity in the context of design, Tauke, Smith and Davis (2015, p. 4) recommend a return to the roots of social and disability activism, to consider ‘diversity to be the end product of a creative process’. They advocate a practice of active engagement that has social justice and inclusivity as the objective, one that recognises ‘design as a material form of social praxis’ (2015, p. 4). This approach aligns with Boys plea to start from disability:

> Delegations toward disability include taking notice of how disabled people explain their experiences; considering the everyday work for both disabled and abled people in living different lives, in their intersections with built space; recognizing the unnoticed assumptions of being abled; opening up to view what constitutes 'normal' social and spatial practices and creatively intervening towards enabling rather than disabling effects; challenging the lack of engagement with dis/ability in architectural theories and practices; and working towards conceptual frameworks and methods which critically and creatively inter-weave questions of form-making with better understandings of how the social and the spatial are entangled. (Boys 2014, p. 191)

Starting from a perspective of 'disability' requires broader recognition of spectrums within the spectrum and an acknowledgement that *normal* is a condition that does not exist. Garland-Thomson (2015) presents a bio-ethical argument for *conserving disability* termed, 'Inclusive world building', a practice also advocating a return to the 'civil and human-rights based understanding of disability'. Garland-Thompson (2015, pp. 1,2) argues that if disability is considered as 'valued social diversity', and as 'natural variations, abilities, and limitations inherent in human embodiment', then 'disability will be understood not as a problem to be eliminated but, rather, as a valid way of being in the world' (2015, p. 1). Egalitarian access will allow for and encourage more diversity in public spaces. This diversity, Garland-Thomson (2015, p. 9) argues, will provide 'individuals and human communities with multiple opportunities for expression, creativity, resourcefulness, relationships, and flourishing'. The benefit and value will not only be for those previously excluded, but for humanity as a whole.

Perspectives that view diversity and difference as part of the spectrum of normal, or that assert normal as a condition that does not exist and instead view ability and dis-ability as concepts and experiences that overlap, are synonymous. The argument for built-environment social justice remains unchanged; urban needs and abilities of all people should be addressed by urban design approaches and practices. By consulting a diversity of perspectives and interrogating what might provide opportunity for connection, there is greater chance of equity.

To do this it is necessary to gain a better understanding of what connection is—to investigate whether connection is actually a relevant concept for people with autism, how people connect to their environments, and to understand why connection is made more easily to some environments than to others? In the next chapter I explore the experience of space to seek answers to these questions. I investigate the cognitive spatial and environmental processes that enable connection and where feelings of connection emanate from. I also discuss the relationship between feelings of connection and connectedness.

chapter 3

The experience of space

The way the world seems is in no small measure a function of how we process the information we receive from the environment

(Kaplan, Stephen & Kaplan, Rachel 1982)

3.1 Chapter layout

This chapter is an investigation into the experience of space. The literature analysed is primarily that of neurotypical understandings. The aim is to surface factors determined responsible for connection to environment, to describe and consider discourse on the psychology and physiology that underlies perception and sensory stimulation, and to explore how those things effect navigation through space. I examine the physiological relationship between people and environment to understand conventional perspective on how connections are made so that I can interrogate why some people feel connected to environments and others disconnected.

To do this, the literature reviewed in sections 3.2 and 3.3 is that of neurotypical, psychological and philosophical perspective. This review provides basis for discussions on urban environmental experience that follows in sections 3.4, 3.5, and 3.6. Work in this chapter explains and challenges neurotypical perspectives and the built environment that they scaffold. In ways consistent with Chapter 2, I have arranged the work into five themed sections. Each section explores a suggestion that I analyse in the context of typical and atypical spatial experience.

Section 3.2, *The experience of space*, is an analysis of the meaning of experience. I unpack the term experience to make clear analyses of environmental experience that follow. Normative literature examined here explains the unique nature of experience and establishes the basis for other investigations in this chapter.

Section 3.3 explores the idea that *our world-space is peculiar and autonomous*. I consider how people perceive, understand, and feel embodiment in space. I consider normative literature on the innate human functions of perception, cognition, and sensory processing, delve into discussion of how they occur, and ask how they might determine a person's understanding of, and relationship with, the world around them. I seek to explain how perception, spatial and environmental cognition, and sensory activity facilitate interpretation, navigation, and wayfinding. I discuss the process of cognitive mapping and consider discourse about how it enables movement through space using memory, perspective, and self-projection. What becomes apparent in this investigation is that differences in these processes likely result in very different experiences of space.

Section 3.4 continues this discussion, and in it I investigate the contention that *public places are spaces sculpted by neurotypical minds and alienate those who interpret their environments in other ways.* Using empirical, including autobiographical accounts, I challenge the provision of true 'universal' access; investigate the lack of holistic consideration in the design of public places; and point to limited understandings of neurological difference. I suggest that because of a lack of understanding of atypical neurological experiences and the influence of embedded ableism, there is little drive to change current practices of shaping urban environments.

Section 3.5 reviews writings on environmental psychology and physiologies of connection. Mindful of the manipulation and contrivance of built form that can influence how people experience space, these writings explore the idea that environments can influence thoughts and feelings. Thus, in this section I examine how *the environment, both natural and contrived, can both shape and nurture our being.* I consider discourse on biophilia and on preferences for order, symmetry, familiarity, pleasure, and anticipation.

Writings on environmental psychology directly explore the relationship between neuroscience and the design of the built environment. This literature directly considers why some people feel like they belong in some places and not in others.

Section 3.6 is about the constructions of connectedness. I hypothesise that *it is a triad of connections—spatial, social, and neurological—that determines understanding, navigation, and feelings about a place, and assert that,* for neurotypical people, *connectedness is paramount*. I investigate this concept of connection and the notion of connectedness for people with autism and consider suggestions that it holds different potency. I reflect on the compatibility between the practices and decisions that determine public space provision, and on the spectrum of users of those spaces. I propose that without an appropriate understanding of the existence and power of connective tissue, people with autism will continue to struggle to find comfort in public spaces.

3.2 The experience of space – a neurotypical account

How does the human body collect, interpret, and understand environmental information? How do people locate themselves and navigate through space? How does the mind propel the body forward—or backwards, or sideways—so that it can occupy its next position in a given geographical context? What cognitive processes are employed to provide certainty about a person's decision to take their next step? In this section I seek answers to these questions.

A person's experience of space occurs through physiological processes reliant upon neurological and sensorial transformations. Experience is a word with myriad applications and contexts. It has both temporal and spatial

dimensions and a relationship with form and is influenced by emotion and cognition. Experience relies upon exposure to, and involvement with, an object or subject in question; it can be described in terms of 'involvement in,' 'contact with,' 'observation of,' and 'familiarity with' both the tangible and intangible (Oxford University Press 2017a). Malpas (1999, p. 16) describes experience as 'human existence as it comprises capacities to think, to feel, to grasp, to act and so on'. The spatial dimensions of experience are contextual; they are tied to location. Malpas (1999, p. 10) suggests, however, that the positional dynamics of experience are operational rather more than simply relational; this 'is not just to say, for instance, that we usually experience ourselves, and other things, in relation to places and spaces, but that the very structure of the mind is intrinsically tied to locality and spatiality'.

These neural workings combine meaning with experience. Meanings are described in terms of the affordances they provide to the individual: 'The meaning of any object, quality, event, or action is what it points to by way of some experience. Meaning is relational, and the meaning of a certain object would be the possible experiences it affords us—either now, in the past, or in the future (as possibilities)' (Robinson & Pallasmaa 2015, p. 35). The meanings developed through and from an experience are stored for use on return to similar situations and transferred from one experience to another, adapting each time to strengthen, weaken, or alter the next experience. Then, on encountering a new space, past experiences act as a library providing reference material of comparative features that assist the new location to become sorted into a space with meaning or to become compartmentalised as a place. In discussions on the notion of place, Malpas (1999, p. 32) suggests that 'place is integral to the very structure and possibility of experience'. The experience of space and its derivative, place, is therefore described as depending on characteristics peculiar to the person, as being influenced by past experience, by the accumulation of past experiences, and as being

shaped by an individual's physiological and neurological responses to the present location.

Thus, the acquisition of spatial knowledge and the processes by which it is transformed into meaningful locational information are inextricably bound with experience. Both the tangible and intangible spaces in which people find themselves will shape their experiences and, as Robinson and Pallasmaa (2015, p. 38) contend, the qualities that spaces offer are primary because their impact is more immediate and a precursor to language and interaction. The component parts of a space or place, the objects of its make-up, are in themselves conveyors of meaning, they are '*events with meaning* that "stand out" within the context of a situation' (Robinson & Pallasmaa 2015, p. 39).

> Objects, then, are clusters of affordances of possible interactions we have had or might have. Objects stand out for us because they are significant for the kinds of creatures we are, with the kinds of perceptual and motor capacities we have, and the kinds of purposes we value and cherish. (Robinson & Pallasmaa 2015, p. 39)

A person's experience of space and the meanings and affordances that shape that experience are unique. Objects and combinations of objects that 'stand out' for one person will differ to those of another. The immediate and instinctive response to an environment and the compilation of previous experiences leading to the current space-time episode, contribute to the personalisation of experience.

Ideas about shared experience are, however, commonly accepted. Either overtly advocated through discourse or rhetoric, or implicitly supported through ignorance or assumption, the idea that a particular place will be

experienced in a comparable way is fundamental to design discourse and practice. The provisions of *place* in an urban environment assume that the users will extract the same meaning and be afforded the same experience. While there is some understanding and recognition that individual choice, ability, preference, and past experience will affect new experiences this understanding does not generally mean people will consider that innate physiological processes used to acquire and translate environmental information may differ from person to person. This assumption is a primary point of contention in this thesis and it is the fulcrum of the investigations of environmental experience in this chapter.

3.3. Our world-space is peculiar and autonomous

3.3.1. The formation of cognitive maps – a neurotypical account

The neural processes described as neurotypical cognitive mapping enable and shape how a person navigates through space using memory, perspective, sensory experience, and self-projection. A cognitive map is a collection of different forms and kinds of knowledge, related and organised by an individual, which, as described above, relies on experience for its formation. It is a summary of experiences and a mental schematic that allows familiarity (Kaplan, S. & Kaplan, R. 1982, pp. 62-63). Environmental information therefore influences processes of cognitive mapmaking and shapes any given resulting cognitive map.

> Cognitive maps are not isolated and contextless entities: they are formed during purposive activity in the everyday world of the child, and, in as much they encode the resources, valued friends, memories, and aspirations as well as factual information about

> geographical layout and routes, they should perhaps better be described as cognitive/affective maps. (Kitchin 1994, pp. 2-3)

Personal cognitive maps are a resource for recognition and familiarity used to understand and navigate environments. The information they store provides a reference catalogue of 'pieces that are connected to each other … these pieces constitute the way we break up our experiences into meaningful parts' (Kaplan, S. & Kaplan, R. 1982, p. 11). The catalogue consists of both foreground and background pieces, of both objects and the spaces in-between them, and it is the process by which these pieces are recognised, then comprehended, then related, then organised, then used, that influences the resultant cognitive map. It is not possible that two cognitive maps can be the same, even for the same person; a repeat journey through the same place at the same time of day, will result in a new or amended cognitive map because every new experience a person has will affect stored information and will by default alter the next experience. They cannot be independent of time or space; they are neither static nor finite but complex and ever changing.

The process of cognitive mapping is deemed fundamental to a person's connectedness to environment. Cognitive mapping describes the method by which a person locates things of value and the enterprise through which a person is enabled to take the next step with certainty. Downs and Stea (2011, p. 312) describe this process as 'a series of psychological transformations by which an individual acquires, codes, stores, recalls and decodes information' about the space that surrounds them. It is the process through which environmental information is synthesised and rationalised, allowing a person to manage large amounts of information in rapid succession (Kaplan, S. & Kaplan, R. 1982, p. 9). Downs and Stea (2011, p. 312) define the cognitive mapping process as follows;

> The individual receives information from a complex, uncertain, changing and unpredictable source via a series of imperfect sensory modalities, operating over varying time spans and intervals between time spans. From such diversity the individual must aggregate information to form a comprehensive representation of the environment. This process of acquisition, amalgamation and storage is cognitive mapping, and the product of this process at any point of time can be considered a cognitive map.

It is theorised that cognitive mapping merges two modalities, spatial cognition and environmental cognition, where spatial cognition comprises the internal cognitive understanding and representation of space (Hart & Moore, 1973 cited in Kitchin 1994, p. 1), and environmental cognition, the information, images, and understandings that a person has about an environment (Moore & Golledge, 1976 cited in Kitchin 1994, p. 1). This duality could more simply be described as the relationship between the corporeal structure of a space and the socio-political meaning of the space or, as discussed in chapter 1, the combination of things that transform a space into a place. Extrapolating then, connectivity to place requires work on two cognitive fronts. It follows, that to achieve relatedness, a person needs to be able to practically locate him or herself in space and determine a directional course through it, while at the same time translating and codifying the inherent meanings specific to that place. The following is a précis of Kaplan and Kaplan's (1982) description of cognitive information processing, which accords with Downs and Stea's (2011, p. 214) assertion that cognition involves problem solving and the ordering and organisation of representations gained through perception.

> It is through the process of perception that a person gains a representation of a space. Space is not made of one representation but of many that require assembly, ordering and prioritising. Each representation is achieved through a filtering process that personalises perception. This process includes at a minimum, the following filters: *simplicity*—the process of discarding information, *essence*—the non-random, systematic loss of information, *discreteness*—the perception of things as distinct from each other and from their surroundings, and *unity*—the amalgamation of things perceived into a recognisable unit. The resultant group of cognitive representations provides an assortment of *mental furniture* requiring arrangement.

The final arrangements of the pieces of mental furniture shape a person's cognitive map. Arrangements will depend on the specific furniture pieces perceived by the individual—those that remain after the filtration process—heavily guided by experience. This intricate and complex process is innately personal. It is prejudiced by both the cognitive functioning of the individual and by the social, political and cultural rules that govern the particular space being processed and navigated. It is a process that is assumed universal by those who plan and construct the built environment.

3.3.2. Taking the next step – a neurotypical account

The processes that locate a body in space are fundamental to environmental perception. Proximity and relativity to people and things locate us and are central to how we experience space. The positioning of one's own body, between one person and another, and of a person to the inanimate objects in their surroundings, relies on the 'acquisition of spatial knowledge' (Burgmanis, Krišjāne & Šķilters 2014). Perception is the threshold of this

acquisition. It is the where and when of sensory procurement; it is the 'neurophysiological processes, including memory, by which an organism becomes aware of and interprets external stimuli' (Oxford University Press 2017b). An inaugural activity; nevertheless, a single perception is always part of something else that has meaning attached to it. Merleau-Ponty (2002, p. 4) positions perceptions into a subjective field-of-view, stating that it is not possible to conceive of an individual, isolated perception. Inherent in this field-of-view are sensations of qualitative measure and it is purported that, 'quality is not an element of consciousness, but a property of the object' (Merleau-Ponty & Smith 2002, p. 5).

This reference to 'the experience error' provides a clue to where the noted 'epistemological shift' might begin (Merleau-Ponty & Smith 2002, p. 5). The *error* occurs with the transposition of already perceived objects—bundled with their inherent meanings—into our consciousness. Merleau-Ponty continues:

> What we know to be in things themselves we immediately take as being in our consciousness of them. We make perception out of things perceived. And since perceived things themselves are obviously accessible only through perception, we end up by understanding neither. We are caught up in the world and we do not succeed in extricating ourselves from it in order to achieve consciousness of the world. If we did, we should see that the quality is never achieved immediately, and that all consciousness is consciousness of something.

If perception is the threshold for the 'acquisition of spatial knowledge', and it is part of a field-of-view of objects impregnated with qualitative sensory characteristics, and the perceiver subjectively holds the field and cannot

extricate him or herself in order to see beyond their subjectivity, then there appears to be no possibility to establish a viewpoint that can represent a benign consciousness; a consciousness that can be built upon to establish shared meaning with others whose field-of-view is markedly different. It can be supposed that commonalities in sensory processing combined with commonalities in socio-cultural experiences will provide opportunity for commonality of interpretations and understandings, but differences in these factors will inevitably inhibit such possibilities. What this association suggests is that the only possible opportunity for aligned understanding of how another person might perceive a space is to acquire their spatial knowledge at the most basic level, by removing all understandings of objects in a field-of-view and wholly accepting another description and interpretation of what is perceived. With this acceptance it is possible that 'the experience error' could be averted. This postulates a seemingly impossible scenario (although one that has possible credibility in the fields of augmented and virtual reality) and inescapable questions fundamental to the inquiry of this thesis remain; how feasible is this process, how reasonable is it to even ask that such a process be undertaken, and if it is asked, how are the depths and parameters of the interrogation determined?

3.3.3. The acquisition of spatial knowledge – a neurotypical account

Of the seven senses, proprioception facilitates bodily awareness and spatial orientation relative to self, and vestibular sense informs a body of balance and identifies movement relative to our bodies in space. Although always affected by the other five senses, proprioception and vestibular sensitivity motivate spatial memory and enable people to establish their frames of reference relative to others and to objects, and they also inform movement and direction.

Having or acquiring spatial knowledge—constructing mental representations of space—are processes that Burgmanis, Krisjane, and Skilters (2014, p. 373) propose are 'constrained' by three interactive factors: (1) 'the frame of reference in which that individual is located;' (2) 'the functional knowledge an individual acquires and uses in everyday spatial processes;' and (3) 'the language that is used in communicating their spatial experience'. Discourse on frames of reference constitutes them as necessary components of cognitive order. Ruggiero *et al.* (2009, p. 2) state that spatial memory is 'intrinsically linked to frames of reference as it is not possible to store spatial information without structuring it according to specific frames.' There are two primary frames of reference: *egocentric* (otherwise known as *autocentric*) and *allocentric.* These frames are the cognitive mechanisms responsible for the performance and guidance of spatial interaction and movement. They are proposed to determine corporeal place attachment or a person's sense of bodily connection to their surroundings (Altman & Low 1992; Malpas 1999; Ruggiero *et al.* 2009).

The egocentric frame of reference is centred on a person's body. It is a person's 'experiential space … and in terms of the sensory, cognitive, and motor capacities of that creature - it is a space that the creature "inhabits"' (Malpas 1999, p. 53). Allocentric frames of reference are centred on an environmental location or feature, whereby 'spatial information is specified independently of the organism's position' (Hoppitt & Laland 2013, p. 3). In terms of connection to place Altman and Low (1992, p. 70) define the egocentric frame of reference as the 'self-centered' perceptive activity that fuses the 'sensations and emotions of general pleasure or discomfort'. It is the perception that determines the value and use of a thing to a person. Altman and Low (1992, p. 70) define the allocentric, 'other-centered' perception as that 'which opens itself to an object, trying to discover the

characteristics that define its general form and its unique identity, which brings an intellectual pleasure'.

The second constraining factor affecting the acquisition of spatial knowledge—the functional knowledge of a space—is the action charged with building spatial knowledge through familiarity; more active environmental processing will generate richer representations (Burgmanis, Krišjāne & Šķilters 2014, p. 382). Spatial knowledge is accumulated through repeated interactions in and with the environment, and the familiarity gained through these interactions also influences the quality of the spatial knowledge gathered 'about locations, distances and directions on various scales' (Burgmanis, Krišjāne & Šķilters 2014, p. 374). It is proposed that the combination of spatial knowledge and social knowledge shape a person's spatial cognition.

Coventry and Garrod (2004, p. 1) see as fundamental to the skill set of all competent language speakers the need to communicate these spatial experiences via language, the third factor thought to constrain the construction of mental representations. They contend that the use of spatial prepositions to describe the location of objects and to find objects after receiving locative information is 'inextricably bound up with the process of seeing our world and acting on it … Spatial descriptions pervade our lives and occur in a wide range of contexts, from locating objects, to reasoning about the world, to understanding the concept of place' (Coventry & Garrod 2004, pp. 13 - 14). Participation in the language of spatial representation and description is an action of communal reinforcement and a process considered critical to the bindings between people who share common spaces.

Thus, the initial processes determined fundamental to the acquisition of spatial knowledge are cognitively complex, but they are only a few cogs in the

network of activity necessary for understanding and navigating environments.

The next task requiring cognitive work is movement. Deciding which way to move through a space depends on the initial cognitive representations processed and the choices available to the individual. To successfully take the next step a person needs to sequence their representations and arrange their mental furniture into a navigable pathway. This activity involves memory, perspective and self-projection.

> A representation is, by itself, a mere building block. It cannot provide us with a conception of what is happening in time or the arrangement of space. To comprehend patterns in time, that is, to be able to relate the present to possible next events, requires that one be able to anticipate, to predict. In terms of structure, anticipation implies some sort of continuity. It implies that one must get from one representation to the other representations if one is to have any conception of what the future might bring'. (Kaplan, S. & Kaplan, R. 1982, p. 40)

Given the sheer volume of information being processed, reliance on continuity seems challenging. Cognition is not a linear process that operates in a convenient sequential manner; one cognitive map rather, is part of a large and dynamic cognitive network and this infers that the potential for dissociation due to missing or incongruous information is great. Kaplan and Kaplan (1982, p. 41) contend, however, that gaps in representations are overcome by connectedness:

> to function, it is not necessary that one know all the possible points between place A and place B. It is only necessary that

> place A and place B be connected – that one can go in general from A to B. Thus connectedness would seem to be sufficient both as a functional requirement and as a means of approximating the experience of continuity.

This explication of connectedness places reliance on association, on memory of past experience, and on spatial landmarks; a ‘creature’s own bodily and environmental awareness … own past and present experience’ are the primary means by which a ‘creature can orient and locate itself’ (Malpas 1999, p. 50). (I insert here a reminder of neurotypical analysis.) The application of these supplementary assets can overcome the absence of immediate representational information. The gaps can be filled. Moreover, these connective assets are the instruments of forward projection. They ‘provide [the] basis for innovation since the connections can relate to each other representations that may have never been experienced together before. Finally, this structure constitutes a basis for anticipation, for prediction of what might be next’ (Kaplan, S. & Kaplan, R. 1982, p. 47). An increase in the quantity and quality of representations should therefore correlate with improved knowing, understanding and navigation of spaces and places.

Critical to the successful acquisition of spatial knowledge is the maximisation of the legibility of place. In the absence of sufficient support from supplementary gap filling connections, legibility will be maximised by access to immediate and reliable representational information. It follows that environments that better facilitate perception and assist with the acquisition of spatial knowledge will be more humanly supportive.

3.4. Public places are spaces sculpted by neurotypical minds; therefore, they alienate those who interpret their environments differently.

Yergeau (2018, p. 37/80 Introduction) states, 'To be autistic is to live and to lie in a between space'. What does this mean in the context of the orthodox understandings of spatial experience and environmental connectedness described above? Is it even appropriate to contemplate the experience of autism in urban spaces in the context of these descriptors? Is Yergeau's 'between space,' as her statement suggests, an autistic space, and is it 'between' because the concept of space is a neurotypically described concept? Yergeau continues, 'These between spaces, then, as they recur across community, discipline, identity, and context, are notable not only for the binds and binaries that they shatter, but for the evidence they leave behind, for their "indeterminacy" [and] … potentiality." (2018, p. 7/75 Chapter 4, citing Munoz, J., Cruising Utopia, p.3).

It is the location and the qualities of these between spaces that I seek to uncover, through exposure of the shatterings, the evidence, the unspecified and the potential.

Public *space* is shared. Public *places* are shaped by social, cultural, and political inputs into a space. The *depth and intensity* of the experience of a public place is regulated by the compatibility between the user and the multifarious composition of the space. The clarity and legibility of a place relies upon perceptive processes and on the cognitive compatibility between the person using it and the expectations and assumptions made by the authors of the space. Reduced compatibility between users, the shapers, and resulting spatial compositions will affect the depth and intensity of

experiences and the legibility of places. Compatibility, on the other hand, will offer comfort.

3.4.1. Neuro-shared and neuro-separate space

Disability geographers assert that shared spaces can be 'hostile and threatening' to people who cannot interpret them (Bertilsdotter, Brownlow & O'Dell 2013). As posited in the introduction to this thesis, 'disability is located within oppressive and excluding environments. By challenging such environments, oppression can be removed or alleviated' (see also\ Marks 1999; Ryan 2005, p. 292). Hansen and Philo (2007, p. 493) advocate for the '"retrieval" of the body in disability studies and, more narrowly, disability geography.' They recommend 'shifting the emphasis from (aiding disabled people in) *doing things 'normally'* to (underlining for all of 'us') simply the *normality of doing things differently*' so that the way in which space is occupied can be re-thought, re-imagined and re-structured (2007, pp. 493, 501). This epistemological shift is a key component and driver for the more general reinstatement of people to the forefront of consideration in the design of the built-environment as advocated decades earlier by Jacobs and Lynch (1961; 1960, 1981). Extending understandings and approaches from the *visually apparent disability and adjunct solution,* to one of *holistic consideration and embedded procedure*, should foster more inclusive built environments.

It is now long recognised that the business of shaping the built environment must include responsibility for the health and wellbeing of its inhabitants. Spatial arrangements in two and three-dimensional form are the practical componentry of architecture and the professional creative practice known as 'urban design.' Mapping out the relationships of internal or external spaces, and between internal and external spaces is the infrastructure of architectural and urban design activity. As the arbiter of these relationships,

the designer is the author of meaning making, and I argue that although meanings will be subjective, they will be significantly more translatable and better understood if the cognitive mechanism of author and user are aligned.

Of prime importance in this alignment is the movement beyond the physical to the mental. Efforts to stimulate improvement, consideration, and recognition of the neurological-geographical divide of the built environment must be positioned as a necessary design imperative. As Sussman and Hollander (2014, p. 8) assert, the 'more you know about human behaviour; the better you can design for it' and their book, *Cognitive Architecture: Designing for How We Respond to the Built Environment*, is a reminder of Jacobs' (1961) thesis that people are a part of nature and our perceptual systems are a product of evolution. Current progress in and enthusiasm for neurological and cognitive research, they contend, continues to stimulate findings in 'evolutionary biology, psychology, neuroscience, or genetics, reframing our understanding of what it means to be humans and how we came to be' (Sussman & Hollander 2014, p. 2). With these improved understandings, it is postulated that better design can be generated—designs that may allow us to approximate better models of *good city form*.

Kitchin (1998, p. 345) states that 'space is socially produced to exclude disabled people in two main ways: spaces are currently organised to keep disabled people 'in their place; spaces are social texts that convey to disabled people that they are "out of place"'. Keeping people 'in their place' is sustained by the provision of 'special spaces for people with disabilities (group homes, sheltered employments)' while less overt 'social texts' are sustained by the more veiled nuances of social interaction (Bertilsdotter, Brownlow & O'Dell 2013, p. 369). For people who find it difficult to occupy shared space, 'special places' can offer relief from social othering, but they

also offer a convenient scapegoat for the broader social conscience by providing *out of sight, out of mind* answers to social challenges.

Kitchin's second form of social exclusion, the subliminal messages that tell someone that they do not belong, are more difficult to extricate because their existence is dependent upon an understanding of other ways of experiencing space. Bertilsdotter, Brownlow and O'Dell (2013, p. 369) discuss this discordance in terms of cognition, dividing space into 'neuro-shared' and 'neuro-separate'. People with autism, they contend, consistently find themselves in neuro-separate space, a space they describe as 'normal' or 'mainstream,' dominated by neurotypical social interaction. In this space neurological difference will be noticed. Gaining access to and participating in the 'social texts' of neurotypically-dominated social space is difficult for people with autism, and for some it is largely impossible. The result is limited or reduced interaction and the potential for increased isolation, with the only option for comfort being 'special places.' Thus, divisive social space production remains firmly entrenched.

In a review of '*auti*-biographies' Baumers and Heylighen (2010) sought to better understand how people with autism interpret and navigate the built environment and explored the relevance of the 'meanings attributed to the built environment' (2010, p. 5). They noted that each of the 'considered auti-biographies reveals an unpredictable feeling with regard to the built environment, resulting from problems or "maladjusted" behaviour they experience in dealing with the physical environment. A recurring problem concerns orientation and wayfinding' (p. 5). The certainty of the built form itself and of static objects in space were described as being compromised and overwhelmed by intangible objects. The confusion experienced was caused by the 'conceived organisation and assumed logic behind the tangible space' (p. 5). These intangible items are the *mental furniture* that Kaplan and Kaplan

(1982) suggest a person needs to arrange in order to orient themselves and navigate through spaces, and the *sensory furniture* that Davidson (2010, p. 306) suggests has the potential to create 'barriers to access' because their 'construction and positioning' is completed by neurotypical others.

Significantly, also, Baumers and Heylighen (2010, p. 6) suggest that the 'authors' perception and interpretation of the built environment—and its divergent dimensions—is shaped by a recurring way of experiencing space: the continuous consciousness of physical space as a tangible entity'.' What occurred, however, were differing sensibilities to intangible entities and a resultant discontinuity of space. The suggested difficulty then, for people with autism, exists because of the inconsistency and unpredictability of other people within a space and because of the intangible items noted above. Because other people cannot be perceived purely as objects devoid of an 'inner self hidden behind the physical,' they are unreliable, confusing the steadfast continuity of the physical space that does exist (2010, p. 7):

> Merely building on directly perceptible aspects to interpret the built environment apparently can lead to problems in dealing with space or 'maladjusted' behaviour, compared to others. Moreover, attributing meaning to the built environment in our society, we begin with a range of non-perceivable, non-concrete information, which gives the tangible space an extra dimension. The built environment surpasses the physical space, and this is field, the authors mentioned above experience their problems, which strongly suggests that their interpretation of the world is mostly based on immediate perceptions of the physical space. (Baumers, S. & Heylighen, A. 2010, p. 7)

Although they recognise theirs as a limited study, Baumers and Heylighen recommend more exchanges with people with autism as a way to reduce the cognitive divide. It is only through the exchange of differing worlds of experience—through exposure of the shatterings, the evidence, the unspecified and the potential—that the perspective of a designer can be broadened to firstly, realise there are 'between' spaces, and to secondly, build the skills necessary for the selection and installation of more appropriate mental and sensory furniture. Such exchange might go some way toward filling, or at least bridging, the described, 'between space' of autism.

3.4.2. Making places and placemaking

A neurotypical mind will design exclusion into the built environment. Moving beyond this mindset requires purposive action. *Placemaking* is a conscious act that spans the social conscience of members of the general populous and of the design professions. The power of place is not a contested phenomenon. Correspondingly, contemporary attempts to mitigate influence and the power of place by means of actively instating character and meaning into spaces does offer hope for broader inclusivity by challenging top-down approaches to design. The placemaking movement was established as grass-roots retaliation against the powers of governments and corporations. For example, The Project for Public Spaces, PPS, founded in the United States in 1975 offers a toolbox of self-help resources for contemporary placemaking activity (Project for Public Places 2009). Now an organisation of worldwide reach, but still quoting the catchphrases of William Whyte and Jane Jacobs, PPS seeks to inspire people to take leadership in transforming public spaces into context-specific and meaningful communal-use places.

> A great public space cannot be measured by its physical attributes alone; it must also serve people as a vital community

> resource in which function always trumps form. When people of all ages, abilities, and socio-economic backgrounds can not only access and enjoy a place, but also play a key role in its identity, creation, and maintenance, *that* is when we see genuine Placemaking in action. (Project for Public Places 2009)

The primary emphasis of PPS activity is in the recognition of the contextual social and cultural identity of place, with the measurement of success of place being one of 'people's health, happiness and wellbeing' (Project for Public Places 2009). In partnership with the United Nations, PPS promotes placemaking as a method to combat issues resulting from rapid global urbanisation. 'More than just promoting better urban design, Placemaking facilitates creative patterns of use, paying particular attention to the physical, cultural, and social identities that define a place and support its ongoing evolution' (Project for Public Places 2009). Importantly also, and contrary to top-down approaches, placemaking acknowledges the dynamic nature of places. The physical characteristics of a space are known as merely the skeletal support for human activity and endeavour, and the actions that take place within recognised as temporal.

Placemaking is central to the *New Urban Agenda*, the idea and document that emerged from the 2016 United Nations Habitat III conference in Quito Ecuador. The *New Urban Agenda* (2016, p. iv) is a 'paradigm shift' that conveys the need to rethink both urban systems and the physical form of urban spaces to achieve for all people, 'equal rights and equal access to the benefits and opportunities that cities can offer' (2016, p. iv). At its core, the idea promotes a participatory model for inclusion in a manifesto that echo back to Lefebvre's work on the right to the city:

> We share a vision of cities for all, referring to the equal use and enjoyment of cities and human settlements, seeking to promote inclusivity and ensure that all inhabitants, of present and future generations, without discrimination of any kind, are able to inhabit and produce just, safe, healthy, accessible, affordable, resilient and sustainable cities and human settlements to foster prosperity and quality of life for all. (United Nations 2016, p. 5)

Thus, there was the paradigm shift promoted by Lynch and Jacobs—*the reinstatement of people to the centre of urban design thinking and consideration of all aspects of human-environment connectedness* (discussed in chapters 1 and 2). And there was the Universal Design paradigm shift—*a shift away from the notion of disabled toward a notion of differently abled* (discussed in chapter 2). To that is added the *New Urban Agenda*, which promotes a shift 'based on the science of cities [and] lays out standards and principles for the planning, construction, development, management, and improvement of urban areas' (2016, p. iv). Have these shifts instituted a better paradigm that is people-centred, holistic and inclusive, and thus principled in its approaches to urban environments?

Through decades of promotion, activism, research, and discourse on people-environment relationships there exist a greater consciousness about and acceptance of the idea that the built environment can significantly affect and influence people's physiological wellbeing. The idea of customising space has been wrested from urban designers, independent and niche community groups, and worldwide organisations such as the United Nations and while placemaking is considered a positive instrument in the fight back against de-humanised urban spaces, the legitimacy of the process is still troubled by questions of ideology and power. Thus, Dovey (2010, p. 3) warns of the placemaking pitfall; 'placemaking – the conscious attempts of designers to

create a sense of place which so easily end up as manipulative corporate formulae or nostalgic ideologies written rather literally into space'.

Describing place as an 'inextricably intertwined knot of spatiality and sociality,' Dovey (2010, p. 6) challenges the contemporary placemaking movement suggesting that there remains a focus on place that is 'closed and stabilizing … inextricably wrapped up with questions of authority and authenticity'. Placemaking proxies, *sense of place* and *essence of place,* have been adopted into design discourse as coercive rhetoric for built environment solutions that provide marketable product for specific locations and peoples. Attempts to install essence, sense and feel—or character—into spaces are often lost in the translation of ideology into practice, in the same way that the provision of equal access becomes reduced to the provision of wheelchair ramps and enlarged toilet cubicles. 'As 'character' becomes coded into either urban design codes or private covenants as a set of formal characteristics, character becomes fixed and reduced to caricature' (Dovey 2010, p. 9).

> The potency of place lies in the ways it becomes taken for granted as a neutral context for every day life, its forgotten-ness … The design of built form involves the production and circulation of non-economic forms of capital. Social capital becomes embodied in places in the best and worst of ways, as mobilization towards a better future and as enclaves of class distinction. Symbolic capital circulates through places and fields of practice; its potency relies on being seen as a form of distinction rather than a form of capital. From such a view, places often camouflage practices of power; distinctions between people are camouflaged as distinctions between places. (Dovey 2010, p. 7)

Dovey (2010, pp. 6,13) recommends a counteractive movement toward 'ontology of place-as-becoming', with focus on the 'morphologies and socio-spatial networks of boundaries and segments; the flows of everyday life; the narratives that are expressed through them; and the desires, hopes and fears that are invested in them'. The recognition of place as an assemblage of non-static, dynamic constructions can prevent a singular power from determining place and give over meaning making to the inhabitants. With this more holistic approach Dovey suggests, it may be possible 'to provide a useful framework for the understanding of place and the practices of urban transformation' (2010, p. 13). While this recipe does not differ from the intent of the *New Urban Agenda,* it does differ in its approach. Dovey's recommendation emphasises that the practice of making places is a human one fought as a continuous battle against the ubiquitous influences of politics and power, rather than one that prescribes a scientific approach operating within a socio-political context.

3.5. The environment, both natural and contrived, can shape and nurture our being

If we are fortunate enough to feel as though we belong in a place, can that place actually have a positive impact on our being? Can an environment, built or natural, combat mental fatigue, nurture or restore to us a state of comfort? And, if this does occur, how does it happen and is it the same for everyone? Do people with autism prefer a particular type of environment and if so, what do these environments offer that others do not?

3.5.1. Emotional responses

It is not difficult to instinctively answer a question about an environment that rests us. For each of us such a question is likely met with imagery of

preferred places and often—although subconsciously—these thoughts are accompanied by a physiological response that sits somewhere on the pleasure spectrum. Therapies of ages have proffered restorative calm through techniques of mental imaginings and meditations that encourage neural transportation to places of calm. Hospitals and aged care homes are aware of the impact of clinical or 'cold' spaces and promote the benefit of more 'home-like' settings. Adjectives such as warm, friendly, restful, supportive, peaceful, fun, inviting and natural, or cold, harsh, unfriendly, confusing and unwelcoming, are used to describe inanimate built-environment spaces. They are accepted as appropriate terminology; there is belief that a person can feel connection with their surroundings.

For the purposes of attempting to expose a 'shattering,' or to surface evidence, in the discussion following I again present a neurotypical line of thought about emotion, feeling, and environment.

The processes by which a person realises feelings about an animate or inanimate object are believed the result of the initial emotional responses to it and, this 'initial emotional engagement with the environment is precognitive or nonconscious' (Mallgrave 2015, p. 20). As discussed in Section 3.2, environmental perceptions are shaped by our sensorimotor system and therefore, as stated by Mallgrave, they 'occur before someone stands back and reflects on the overall experience' (p. 20).

> The general ambience of a perceptual field is what people first encounter … And biological judgements are already being made by such things as the touch of a door handle or handrail, the proportioning of stair risers and treads, the texture of the floor material, the resonance or ambience of the spaces, the hand of

> fabrics, the smell of materials, and the presence of natural light. (p. 20)

Emotional responses generally fall into two categories, sympathetic and parasympathetic. These two responses operate by means of reciprocation and opposition and, as Mallgrave suggests, they are informative processes important to built environment practice. Efforts by designers to detect and understand emotional responses can greatly benefit design solutions. Understanding what is required to evoke emotion, or just as importantly, what is to be avoided, can provide a designer with powerful design tools. Emotional responses are generally understood as being subjective. How one person feels about a place can be markedly different to another. 'A building can arouse our metabolic systems and demand high energy expenditure, or a building can provide a place of relaxation and comforting sociability' (Mallgrave 2015, p. 22).

The methods by which emotional responses to objects and to place occur are debated. One theory contemporarily holding a level of consensus—in neurotypical discourse—is that emotional responses can be attributed to a neurological 'mirror system.' This is a system that enables 'our finely tuned abilities to understand and empathize with the behaviour of others, but more generally the way that our minds connect to our surroundings' (Ellard 2015, p. 20). Both Ellard (2015, pp. 20 - 22) and Mallgrave (2015, pp. 22 - 29) suggest that it is the human mirror system that is responsible for empathic response to environment. For example, 'in witnessing someone in pain, we map the area of trauma onto our own bodies', and similarly, by way of 'proprioception in the sense that we seem to enjoy the movements of a ballet dancer not just visually but also motorically' (Mallgrave 2015, p. 23).

A possibility described by Mallgrave (2015, p. 23) and discussed by others is that some neurological workings of autism may 'result from a breakdown of a mirror system' (Dapretto *et al.* 2006; Frith 2001; Hurley 2008; Lombardo & Baron-Cohen 2011). This is a process linked to Baron-Cohen's theory of mindblindness (1995), or Theory of Mind—a theory critiqued as neurotypically devised and one that is highly contested. Because there is debate about the standing, the neuro-scientific processes, and relevant applications of this proposition, I advance the discussion here as both theoretical and speculative. The hypothesis suggests that for people with autism the ability to map empathic or emotional responses from animate or inanimate objects is diminished. Without such a response, it could be expected that there would be an entirely different environmental experience and, this alternative experience would remain unavailable to and unappreciated by others whose mirror systems remain intact. Further to a suggestion by Baumers and Heylighen (2010) that limited access to the intangible entities in a space will lessen opportunity for representational gap filling, there would be greater reliance on tangible entities that map more easily to cognitive expectation.

Following the argument of diminished mirror system response, the tangible features of an environment that emulate order, provide stability, and allow time for reciprocal and opposing emotional responses, will be given preference—or more relied upon—than those that do not. Tangible features offering reliability provide greater opportunity for mirror response, however, for people whose responses are less responsive, the gaps between the tangible are less likely to be filled by any trustworthy meaning. As a consequence, the environment will be less understood and more difficult to navigate. This proposition suggests that the provision of consistent and reliable tangible objects will offer greater opportunity for emotional response

and better support cognitive mapping processes, thereby providing higher levels of environmental comfort.

It is reasonable to suspect that consistent and reliable tangible objects will improve environmental reliability, but explanations based in mindblindness, Theory of Mind, and mirror system responses are problematic. Yergeau (2013, p. 8) asks, 'Would we have a theory of mind without autism?'

> My argument here is that theories about ToM impact the autistic bodymind in material and violent ways. My argument here is that denying autistic selfhood and denying autistic corporeality and denying autistic rhetoricity reifies systemic abuse and ableism. My argument here is that autistic people have come to represent a tidily bounded limit case that signifies what it means to be inhuman—all in the name of empiricism, all in the name of ToM (Yergeau 2013, p. 14)

Emotional response to environment does occur and it should be considered important to the practice of shaping urban environments. Understanding how and why it occurs and having the ability to tap into those understandings would provide an invaluable resource. For now, however, I place this discussion into the category of *the unspecified and the potential,* with a view that consulting alternative perspectives will likely provide exciting material for urban shapers.

3.5.2. Environmental preference and restorative environments

A preference for stability, reliability, and coherency in an environment is, likewise, a theoretical concept of human cognitive activity termed *environmental preference*. *Environmental preference* describes the human

predisposition toward effective and capable functioning (Kaplan & Kaplan 2011, p. 311). It relies upon the coherence and legibility of an environment and whether information is immediately evident or must be inferred. Kaplan and Kaplan (2011, p. 312) submit that in 'settings where familiarity is lacking it is thus particularly important to have supportive cues that facilitate understanding and exploration'. The ability to confidently take the next step in any environment is submitted as reliant upon rapidly assessing possibilities and anticipating outcomes, and this process is best supported by clear and decipherable information. Although mostly subconscious, the mental work required to undertake these processes requires constant focus. It is the process described and termed *directed attention* (Joye *et al.* 2013; Kaplan & Kaplan 2011).

Urban environments are places of high cognitive demand and present a constant requisite for action. This persistent and demanding activity can result in mental fatigue or, as Joye (2013, pp. 2 - 3) explains, it 'can run out of energy when it has been used too intensively for a prolonged period of time, leading to directed attention fatigue.' Combatting this fatigue requires a restorative process that allows a reduction in the amount of effort needed to operate, one that is less demanding because it is more in tune with a person's cognitive processes (Kaplan & Kaplan 2011, p. 313). *Attention Restoration Theory* outlines a process that explains how this restoration occurs, and central to this theory is the notion of *fascination,* and the ability of natural environments to provide the necessary components for the recovery of a person's attention fatigue (Berman, Jonides & Kaplan 2008; Joye *et al.* 2013; Kaplan 1995). Fascination is described as a process requiring less cognitive effort.

> The focus on effort is because restorative experiences are thought to hinge on the relative effortlessness with which natural

> environments are visually processed. Specifically, environments that support individuals functioning in a relatively effortless mode can provide – if needed – an opportunity to replenish depleted attentional resources … natural elements or scenes are considered to be intrinsically more fascinating, or to contain many more fascinating features or elements than urban environments. (Joye *et al.* 2013, p. 2).

Joye (2013, p. 3) proposes there are three restorative components of natural environments that facilitate fascination: (1) the provision of a feeling of mental or physical removal from attentional demands; (2) distraction by the richness and profusion of parts which can hold interest in pockets of detail and at the same time allow the environment to be seen as an integrated entity; and (3) less demand on the directed attention needed for behavioural responses due to greater compatibility with the demands of the natural environment.

While Joye's first restorative component is easy to appreciate, the second is compelling because it suggests a connection between the described phenomena and the psychological theory of gestalt perception. Explained as a visual, relational concept, gestalt perception describes the ability of people to determine meaning, or 'big-picture concepts', from an overall perceptive field rather than from the sum of its independent parts (Cashin 2005, p. 27). While the independent parts of a field of view may each hold their own meaning, the gestalt delivers a 'shape, pattern, or structure, which as an object of perception forms a specific whole and has properties, which cannot be completely deduced from a knowledge of the properties of its parts' (Bogdashina 2003, p. 82).

In the context of this research, that correlation has significance because one of the advised—albeit clinical—characteristics of autism is limited gestalt perception, or a tendency to focus, sometimes obsessively, on the detail of the parts rather than the whole. And, for some, the parts themselves can be perceived literally (Bogdashina 2003; Cashin 2005). The theory suggests, therefore, that for some people with autism, the big-picture concept can remain undetected. What is also possible is that the overall scene can become unrecognisable if a small part of a field of view is changed. In unnatural—or constructed—environments, the ability to perceive the concept of *place* (as described in chapter 2, section 2.4), or to understand the big-picture, is surmised as a key to connection. It is proposed that if a person does not perceive a 'specific whole,' then making connection to it will be difficult. Natural environments, however, that allow interest in pockets of detail, do not demand an understanding of a thematic big-picture concept that is most likely different to the pocket. Instead, the detail of the pocket is directly relational to the detail of the whole. In naturally occurring environments the pocket of focus represents a proportional and logical geometric component of the larger integrated entity allowing a more holistic feeling of connection to the 'specific whole.'

Joye's third restorative component—greater compatibility with the natural environment—refers to human biological connection. This component proposes that the natural environment does not require anything of a person that is not easily delivered. Biological connection suggests that evolution continues to determine human preference for natural surrounds and that this preference is attributable to the innate effortlessness with which natural things are comprehended. Neuro-scientific research now confirms that the benefits of nature are more than just a romantic idealisation (Van Den Berg, Hartig & Staats 2007). One major characteristic of the people/nature congruency is described in terms of mathematics and geometry, or pattern

and rhythm. It is proposed that human brains correspond to and pursue naturally occurring mathematical structures (Ellard 2015, p. 38; Mikiten, Salingaros & Yu 2000). The structures are explained in terms of fractal properties, or as 'scale invariance' whereby 'the basic shape that you see is repeated over and over again' (Ellard 2015, p. 38). Fractals are geometrically hierarchical, connecting levels of scale in systematic and proportional ways therefore they can effectively simplify the translation of complex form (Mikiten, Salingaros & Yu 2000, p. 64). Mikiten, Salingaros and Yu (2000) propose that the systems of the human mind and brain partially operate in this fractal way.

> Systems in the body are "tuned" to generically recognize different kinds of fractal hierarchies. We contend that the brain has special systems which are tuned in exactly this way. The brain's neural patterns are responsible for recognizing structured systems that have a hierarchical organization in which the levels in the hierarchy are defined in a systematic, algorithmic way. (Mikiten, Salingaros & Yu 2000, p. 66)

This system, they assert, is a shared language that provides emotive value and allows for the transfer of meaning via a system of rules that govern 'syntax and semantics' (Mikiten, Salingaros & Yu 2000, p. 66).

Ellard (2015), Sussman and Hollander (2014), and Robinson and Pallasmaa (2015) also discuss natural preference as an innate human condition. Ellard (2014, p. 31) states that 'we still possess faint echoes of some deep, primal connection with the kinds of environment that shaped our species'. Sussman and Hollander (2014, p. 1) refer to modern humans as a 'recent species' that carries 'significant baggage from a very long journey', stating that, 'Our sense of aesthetics is at root biological, evolving over millennia'. Pallasmaa (in\

Robinson & Pallasmaa 2015, p. 62) states that, 'We need to accept the essential historical and embodied essence of human existence, experience, cognition and memory'. In essence, their contention is that human biology continues to determine preference and comfort, that there is 'neural ground for our fundamental spatial and environmental pleasures and displeasures—as well as our feelings for comfort, safety and fear' (Robinson & Pallasmaa 2015, p. 63).

It is not suggested that purely natural settings as opposed to urban settings offer the only opportunity for restoration; 'natural and built environments can have different restorative potentials with regard to the presence of restorative qualities in conjunction with personal needs and characteristics' (Van Den Berg, Hartig & Staats 2007, p. 84). What is suggested is that natural environments, or more natural settings, offer things that accord neurologically with human wellbeing. It is also proposed that the instinct to seek out nature for relief from urban intensity and incongruence is primal. Exposure to nature can affect mood and the ability to think, it has 'significant psychological effects that carry through all the way to crime rates, liveability, and happiness in urban environments' (Ellard 2015, p. 37).

The language of geometric and rhythmic form, hierarchy, and symmetry have long been integrated into architecture and design—consider the endurance and impact of Roman temples on contemporary built form—and besides the structural integrity of the compositions there exists a language of accordance in the composition that resonates harmony. In 1984, Wilson defined the human need for biological connection as *biophilia* (Kellert & Wilson 1993). Since Wilson's hypothesis the concepts of *biophilic architecture* and *biophilic design* have mobilised deliberate attempts to instil natural elements into the built environment to provide a conduit between people and the natural world. The intent is biological connection and restoration. Proponents of this

approach draw evidence for the positive effect of exposure to nature from history, anecdotal and empirical evidence, and from more contemporary neuro-scientific and psychographic research (Ellard 2015; Robinson & Pallasmaa 2015; Sussman & Hollander 2014). The approach is not new but the phraseology and the scientific rationale of support for the relationship now provide a more admissible basis for its success, as the discussions above describe.

Preference for natural environments is, at root, intrinsically human. Restoration is more often sought and found in places that offer contact with nature (Ellard 2015, p. 30; Matsuoka & Kaplan 2008). Whether people with autism have a greater or lesser craving or need for natural contact cannot be asserted but there is support for the idea that natural relationships are both important and restorative. Some of the defining characteristics of autism described by DSM-5—high sensitivity to environmental changes and intense focus on some items—suggest that both the reliability and proportionate predictability of a natural scene could provide cognitive comfort more readily than an unnatural one. Davidson and Smith's (2009) study of forty-five autistic autobiographies describes the significance of the relationship between people with autism, 'non-human others' and the natural environment as an 'emerging theme'. Davidson and Smith (2009, p. 898) assert that the autobiographies studied revealed 'often intense, emotional relations to "natural" things and places', and that these relationships constitute a significant, meaningful and rewarding part of people's social lives.

> I can only afford a certain amount of time among humans, and if don't get to moving my senses will overload, and the rest of the day I will have to put myself in the quiet of my room, and miss out on the trees and rocks and streams that talk to me so much

> more gently than any human. (Autobiography MM in Davidson & Smith 2009)

This type of social connectedness they contend, while not unlike the experience of neurotypical people, describes a different way of thinking about what it means to be social.

> Thus, we begin to see that, while ASD authors cherish protected time and territory, the space they require to sense safety is not necessarily the 'empty' space (or fortress) of aloneness. It may be unpopulated by people, but the environment they desire can still be alive with nonhuman otherness, in whose company a rich and rewarding range of positive emotions can be experienced: in other words, they develop unusual or atypical emotional geographies. (Davidson & Smith 2009, p. 907)

3.6. It is the triad of connections—spatial, social, and sensorial—that determine how we feel about a place; connectedness is paramount

Salingaros (1998) states that a 'central component of the human intellect is the ability to establish connections'. In Chapter 2, I proposed this thesis to be a search for the substance that strengthens connections because the associations between people, and/or between people and environment can facilitate feelings of belonging and furnish meaning. I adopted the definition of connectedness advanced by Hagerty *et al.* (1993, p. 293) that requires a person be actively involved with other people or environments and derive 'comfort, well-being and anxiety-reduction' from that interaction. Chapter 2 focuses on urban design and public space and the processes involved in their

making. This chapter investigates and speculates on spatial and environmental experience.

The investigations in these chapters suggests that connectedness has three properties—spatial, social, and sensorial—and that a personally attuned balance of those properties is required to achieve a person's 'comfort, well-being and anxiety-reduction.' Spatial, social, and sensorial connectedness properties are further defined by temporal considerations and by subjective feelings. I posit that environmental meaning is a mix of this weighted connectedness triad and will resolve feelings of comfort-discomfort, ease-unease, predictability-unpredictability, confidence-fear, congruity-incongruity, inclusion-exclusion, and pleasure-pain. Importantly though, without explanations of non-neurotypical experiences from the experiencers, it is not possible to confirm that these are the only factors in play, nor is it possible to unravel their interdependencies, nor to assess their weighted importance. It does not seem plausible to separate connectedness factors at all so that they might be evaluated independently. Rather, they appear to be instinctively co-dependent and collaborative. For example, discomfort felt because of the *spatial* overcrowding of a place can be easily recognised, but its separation from the *sensorial* and *social* influences experienced by one particular person at that particular moment in time is not possible. The combination of these connectedness factors (and those yet to be identified) produces unique experiences and for each of us it is their weighted collaboration that ultimately determines legibility and congruity and therefore, our degree of access and feeling of belonging to the built environment.

Contemporarily, psychological insight into how people occupy and navigate space, and recognition that meaning is instilled into places, are central to psycho-geographic discourse and these understandings have increasing

traction in architectural and urban design conversations. ‘Not only do designers and architects have at their disposal a wider variety of materials and methods than at any time in the past, but there is also increasing penetration of the guiding principles of the human sciences—sociology, psychology, cognitive science, and neuroscience—into the applied world of design’ (Ellard 2015, p. 38). The processes involved in shaping urban environments and creating public places within them, therefore, should become increasingly endowed with atypical neurological experience and perspective. Seeking authentic perspective to gain lived experience is key to broadening and improving feelings of built environment connectedness, but it is also necessary to unpack existing theories and to challenge stereotypical understandings.

In the next chapter I explore qualitative methodological precedent and processes used to gain perspectives and contribute to understandings of experience. This cross-disciplinary investigation necessitates review of approaches that are appropriate to the domain of urban design, to environmental experience, and to (and for) autism. Chapter 4, *Methodological wayfinding*, begins Part 3 of this thesis, *Giving Voice*.

PART 3

GIVING VOICE

chapter 4

Methodological wayfinding

We are buried beneath the weight of information,
which is being confused with knowledge

Tom Waits
(http://www.brainyquote.com/quotes/authors/t/tom_waits.html)

4.1 Chapter summary

The aim of this chapter is to provide methodological foundation and precedent for this cross-disciplinary investigation into the experiences that people with autism have in public places. The lack of research with this specific focus impels consideration of approaches that are applicable to, and respectful of, all relevant disciplines.

In this beginning chapter of *Part 3*, *Giving Voice*, I discuss methodological approaches used in previous investigations with focus on autism and those commonly applied in the field of urban design. I provide this juxtaposed discussion to establish background and legitimacy for my research design, which is detailed in chapter 5. As noted in *Chapter 1, Introduction*, section 1.3, *Input from people with autism has far greater capacity to ensure authenticity and in doing so make meaningful contribution.* Described in section 2.5.3 is the objective of the Autism Self Advocacy Network to empower and support autistic people through a tenet of 'nothing about us without us.' The focus of the methodology exploration in this chapter is how to best gain that input.

I have divided this chapter into four sections: Section 4.2, *Autism and research*, describes traditional approaches to autism research that conventionally positioned it as a disability. Section 4.3, *Giving voice to autism*, describes contemporary approaches to accessing individual autism voices, and outlines the importance of, and the difficulties associated with that work. Section 4.4, *The built environment urban design and shared urban space – multiple voices*, focuses on theoretical and practical approaches to research in disciplines that contribute to urban design. Section 4.5, *Tailoring qualitative mixed methods* introduces the methods used to document the phenomenological experiences and insights of five people with autism.

4.2 Autism and research

Since the inception of the terms *Asperger's* and *Autism Spectrum Disorder* in the 1930s, methods used to build understandings and formulate treatments for autism were founded on doctor-patient, able-disabled, and normal-abnormal practices. Autism was 'viewed as a biomedical condition, highlighting deficits in social interaction and communication' (Bagatell 2010, p. 33). Until the latter decades of the 20th century this biomedical perspective constituted human difference as abnormal and requiring correction and positioned all 'disabled people' into medically-based frameworks emphasizing behaviour modification and cure (Bagatell 2010; Mertens, Sullivan & Stace 2013). The medical model supported a clinical paradigm wherein autism diagnosis and research were seen as the remit of positivist psychology and neurology. Until recently therefore, approaches to autism research were limited to methods congruent with their epistemologies.

The medical model of disability relegates to an *otherly* status people who do not embody the norm. The discourse and changes associated with the disability and social rights activism of the1960s and 1970s had impact on perspectives and attitudes, and together with technological advances, facilitated shift in the disability model. The emphasis of this change was on, 'what society should and could do to improve the lives of disabled people, centrally including demands for improvements in the accessibility of the built environment' (Boys 2014, p. 20). Gradually, the matter of disability moved to a more socially minded arena with the *social model for disability* recognised as an appropriate starting point for addressing issues and backgrounding conversations about disabling societies (Mertens, Sullivan & Stace 2013).

In 2001 the World Health Organization introduced the *International Classification of Functioning, Disability and Health* (ICF), in an effort to shift focus from the 'limitations of people's abilities as the key determination of disability' (Imrie 2004b, p. 288). In 2006, the United Nations, updated Article 1 of the *Convention on the Rights of Persons with Disabilities* (2006, p. 4):

> The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
>
> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

These enlightened principles assisted in placing questions around the definitions of *able* and *disabled*, *normal* and *different*, and compelled alternative, more constructivist, and more holistic approaches to research. New ideas about the 'various barriers' of hindrance promoted efforts to understand varied experiences, demanded alternative techniques, and more empathetic perspectives on investigation and interpretation of experience. However, even with this more sentient top down pressure and bottom up activism to broaden and enlighten perspectives and to promote progression toward more socially based attitudes and frameworks, the medical perspective continues to permeate discourse, specialist advice, and application. The term *disability* for example, still has hold. Boys (2014, pp. 20-22) describes the medical to social model shift as 'very important in the history of disability activism', but emphasises there is need to 'take note of the many strategies and narratives of disabled people themselves, and to

engage more critically with the unspoken assumptions behind what constitutes being *abled*.' A comprehensive and complex web of ontological positioning challenges the task of effecting change. 'The pathway to full realization of human rights and social justice is not smooth. A history of oppression and neglect has to be overcome' (Mertens 2007, p. 498).

Within the practices of qualitative research—which are both embedded in and at the forefront of human rights realisations—vestiges of past attitude and approach still have grip. These perspectives continue to permit and to perpetuate ableism, giving strength and credibility to the power dynamic between the *researched* and the *researcher*. Mertens, Sullivan and Stace (2007, p. 476) go so far as to suggest that social research is 'complicit in fostering oppressive stereotypes of disabled people'. Smith (1999) describes current positioning as beholden to the legacies of 'colonial' perspective and application, and in 2018 Denzin and Lincoln (2018, p. 9) and Erickson (2013, pp. 89-124) still allege that colonial legacy is well entrenched in qualitative research practices.

> From the vantage point of the colonized, a position from which I write, and choose to privilege, the term 'research' is inextricably linked to European imperialism and colonialism. The word itself, 'research', is probably one of the dirtiest words in the indigenous world's vocabulary … It appals us that the West can desire, extract and claim ownership of our ways of knowing, our imagery, the things we create and produce, and then simultaneously reject the people who created and developed those ideas and seek to deny them further opportunities to be creators of their own culture and own nations. (Smith 1999, p. 30)

Challenges to colonial research legacy and those borne out of eradicating and replacing traditional research methods have spurred alternative approaches to systematic inquiry. Denzin and Lincoln (2018, pp. 4-8) describe a series of qualitative research 'paradigm wars' that have been playing out since the 1980s, where vying interests and opinions debate politics and procedure, the subjective and objective position of the researcher, and the conventions of fact verification. Denzin and Lincoln (2018, p. 9) currently position qualitative research as textual narrative: 'The province of qualitative research, accordingly, is the world of lived experience, for this is where the individual belief and action intersect with culture. Under this model, there is no representation and description'.

In the context of *disability* communities, Mertens, Sullivan and Stace (2013) ask, 'Is there a research paradigm that is able to capture disability as a complex, embodied relationship between people with impairments and their natural and social environments'? Mertens (2007, p. 212) earlier proposed a 'transformative paradigm', a mixed methods proposal that addresses issues of power, recognises that realities are socially, politically, culturally, economically and racially/ethnically based, and one that has purpose to provide basis for social change. 'The transformative paradigm with its associated philosophical assumptions provides a framework for addressing inequality and injustice in society using culturally competent, mixed methods strategies' (Mertens 2007, p. 212). I discuss the relationship between transformative paradigm methodology and the current investigation in the following section.

Respectful, non-stereotyping, and balanced research methods are therefore subject to a constant state of their own interrogation and exploration. For research based in the domain of *disability,* movement away from the label and away from imbalanced qualitative research approaches that claim ownership

of knowing is still impeded by culturally embedded and institutionalised epistemologies. Autism-specific research, which remains part of the disability paradigm, is still struggling to find its voice. Gray (2001, p. 1250) for example, contends that service agencies still operate within terms of 'an illness ideology relevant to the disorder they treat'. Gray (2001, p. 1250) provides the following sombre description of one such state run agency:

> The autistic centre in this research was no exception to this tendency. The centre staff generally accepted a biomedical model of autism that assumes it to have a biological, probably genetic etiology, and a poor prognosis. The staff also followed a grief model of adaptation for the parents that assumed that the onset of autism in a child to be a loss comparable to a death, and that parents would typically follow an emotional pattern of ''peaks and troughs'' as they gradually came to terms with their loss.

This negative, *othering* perspective contributes to the comparatively small amount of autism-specific, built environment research. It means that researchers have had little determination to understand the experience of autism in the built environment and that individuals with autism have had little opportunity to convey lived experiences. Autism research in general has had significant growth. Based on research funding allocation, an increase of 64.3% occurred in the United States between 2008 and 2016 (Interagency Autism Coordinating Committee 2019). The Autism Cooperative Research Centre (2019) based in Australia reports that between its inception in 2013, up to 2017, autism research investment increased from 40 grants and $14 million, to 113 grants and $44 million. What has also progressed during this time is the emphasis upon whole-of-life experience and movement toward a more collaborative approach to research. People with autism, their families,

and carers are now more likely to be included into conversations about their experiences and also about how research itself is conducted.(Fletcher-Watson *et al.* 2018).

The overall increase in autism research and greater emphasis on cooperative research has surfaced needs for more and for improved participatory methods. (Fletcher-Watson *et al.* 2018; Griffith *et al.* 2012) Fletcher-Watson *et al.* (Fletcher-Watson *et al.* 2018, p. 1) assert that the increase in autism research has not necessarily delivered satisfactory outcomes and note there is need for the 'development of participatory research skills among the autism research community and the facilitation of greater autistic leadership of, and partnership in, research … to overcome barriers to effective translation and to ensure that research yields relevant benefits'. Griffith *et al.* (2012)—with focus on Asperger's—note that of the small amount of research undertaken, the majority has focus on children, not the subjective experiences of adults who, in their study, reported wanting to 'remain as independent as possible'. Participatory research is necessary for the dissemination of different experiences. It addresses power imbalances and *othering*, helps to correct errors of past assumption, bring new directions into focus, and to tease out the autistic stereotypes that permeate the bio-medical approaches of the past.

The diversity of autism has always been acknowledged by the use of the term *spectrum* but the lack of experiential input into research has contributed to stereotypical assumptions about positions within the spectrum. Individuals cannot be definitively grouped and collectively defined by the spectral positions of their diagnosis. Assumptions cannot be made about commonality of autism-related tolerances and intolerances, or of likes and dislikes. Positioning individuals with autism, or those diagnosed with Asperger's, as an undifferentiated and homogenous group is not respectful of

the person and is incongruous with this research. To access and encourage individual stories it is necessary to be sensitive to, and respectful of, the idiosyncrasies of each person. This approach means allowing for inconsistency in process to accommodate the specific preferences, wants and needs of each participating individual so that the comfort and contribution of each person can be maximised.

4.3 Giving voice to autism

Giving voice to marginalised groups is a critical component of contemporary qualitative research. As stated by Mason (2002, p. 1) the qualitative process 'engages us with things that matter, in ways that matter', and I propose that what matters is the exposure and recognition of experiences that offer insight into alternative ways to be in a space. What matters is giving voice to people who do not recognise themselves in normative and neurotypical analysis of experience in the built environment. For the shapers of urban places, what matters is enlightening their approaches and their practices by foregrounding alternative experiences and surfacing the effect of their actions. For people with autism who experience discomfort in, or exclusion from public urban places, what matters is finding comfort and feeling included. The primary objective and necessary first step in the process of engaging with these things is to reveal lived experiences and to re-present them as honestly and respectfully as possible. This work is done in an effort to unearth underlying assumptions and prejudices that cloud current urban design theory and practice.

Seeking out and attempting to give voice to people with autism who are more likely to remain isolated and retreat from exposure, requires not only a tailoring of select qualitative methods, but also maximum emphasis on flexibility in procedure and reflexivity during process. The empirical realities

sought and then documented in chapters 5, 6, and 7 are intentionally personal, subjective, and contextual. They provide detailed reflections of individual experiences of people whom self-identify with having autism. By definition, these experiences are, on a neurological level, mostly inconsistent with those of neurotypical people because neurotypical functioning prohibits a non-neurotypical perspective (Newman, Cashin & Waters 2010). The nature of reality experienced by participants in this study or, the 'nature and essence of things in the social world' as perceived and communicated by participants (Mason 2002, p. 14), is innately different to my own reality because my lenses are neurotypical.

> there is no clear window into the inner life of an individual. Any gaze is always filtered through the lenses of language, gender, social class, race, and ethnicity. There are no objective observations, only observations socially situated in the worlds of—and between—the observer and the observed. Subjects, or individuals, are seldom able to give full explanations of their actions or intentions; all they can offer are accounts, or stories, about what they have done and why. (Denzin & Lincoln 2005, p. 21)

In this research, differences in ontological perspective are compounded by the potential for neurological processing differences. Not only are the perspectives of participants filtered through my own lens they are likely filtered via neurological processes that are structurally different. Sinclair (1993, p. 1) describes this lens—discussed in chapter 1—as 'pervasive' and inseparable, colouring 'every aspect of existence'. The processes associated with individual neural detections and interpretations of reality are so fundamental that it is typically not possible to be aware of them until later

reflection, and, in some contexts, it may not be possible to recognise them at all. Mason (2002, p. 14) advises:

> it is only once it is recognised that alternative ontological perspectives might tell different stories, that a researcher can begin to see their own ontological view of the social world as a position which should be established and understood, rather than an obvious and universal truth which can be taken for granted.

Cousin (2009, p. 13) states, 'The point of research is to enable us to make informed judgments about what might be going on within and beyond the situations we are researching'. For situations that are unfamiliar or contrary to our own, understandings must be advanced in a way that allows honest representation. This becomes difficult when the worldview of a participant sits outside of the worldview of a researcher, not only on a socio-political and cultural level, but also on an essentially innate and nebulous, intellectual level. Because the necessary 'informed judgments' of the researcher rely upon an equivalent *inquiry paradigm,* they remain dangerously open to bias and assumption.

> Paradigms are deeply embedded in the socialization of adherents and practitioners. Paradigms tell us what is important, legitimate and reasonable. Paradigms are also normative, telling the practitioner what to do without the necessity of long existential or epistemological consideration. But it is this aspect of paradigms that constitutes both strength and weakness—a strength in that it makes decisions about what to do relatively easy, a weakness in that the very reason for a certain decision is hidden in the unquestioned assumptions of the paradigm. (Cousin 2009, p. 13)

The transformative paradigm discussed above, attempts to address the worldview predicament by forming a partnership with participants, by using mixed methods that are 'culturally respectful' and 'supportive of diverse needs', that recognise 'multiple dimensions of diversity', and that necessitate working together so that 'oppressive structures' can be challenged (Mertens, Sullivan & Stace 2013, p. 483). It is a paradigm focused on bringing the researched and the researcher together in a combined effort to seek social justice and effect social transformation. The transformative paradigm for qualitative research is a head-on challenge to bio-medically based practices, intended to engage with things that matter. It is, however, a paradigm, and as such it is still open to bias and assumption.

The transformative paradigm does provide some basis for the approach I use in this thesis, however its occupation with agenda transcends my focus. For this research it is critically important to be culturally respectful, be supportive and recognise dimensions of diversity, and to work as collaboratively as possible with participants, but I have no social justice agenda. It is possible there could be some contribution to social transformation, but until the experiences, needs and wants of individuals are revealed there cannot be assumption about what changes are necessary or more importantly, whether my co-researching participants believe that change is necessary.

There is, however, no paradigm for Sinclair's described 'way of being' (1993, p. 1), for the processes of neural detection and association that colour: 'every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence'. For those understandings there is only reliance upon a relationship of trust and respect and a means of communication that preferences the provider of the information through the

provision of methods that offer choice and flexibility. Giving voice to autism is about the provision of a participatory opportunity that reverses the traditional power roles of the researched and the researcher.

As a 'geographically dispersed community defined by disability' autistic self-advocates experience less opportunity for collective expression (Nicolaidis *et al.* 2011, p. 143). Unlike minority groups such as those defined by race, ethnicity or socio-economic status, people with autism are dispersed throughout a population. Consequently, clearly defined and cohesive autistic communities have been slower to organise, they remain more commonly disparate, lacking a consistent agenda or unified voice (Nicolaidis *et al.* 2011). Nicolaidis *et al.* (2011, p. 149) suggest that although there is an emerging and strengthening 'autism self-advocacy movement', the challenges faced by such communities are great; making difficult the establishment of a framework for community based participatory research (CBPR):

> Including autistic self-advocates as equal partners in CBPR requires significant attention to infrastructure and practices that equalize power and accommodate diverse needs … effective collaboration entails a constantly evolving process to meet each new challenge.

Individual and original stories therefore contribute to the formation of community-building advocacy. Baumers and Heylighen (2015) recommend the value of individual story telling in an article describing the experience of Roland, a man with autism who documented the process of designing his own living spaces. They argue that through a singular telling it is possible to expose and force reflection on our own experiences; 'we situate the value of our exploration of Roland's particular design approach in the incentive to raise questions about issues that seem to be taken for granted in our own

context of designing' (2015, pp. 13-14). The intention of Baumers and Heylighen was not to narrow things to a particular happening within a particular context, but to dissect experiences and allow room for reflection on the underlying processes.

Autism communities and autism advocacy have evolved through online communication. For people with autism, advances in technology, especially personal computers and social media, have enabled and encouraged greater communication. Both individual and collective voices now have greater opportunity for connection to each other and to neurotypical people. There are two rationalisations for the preference for internet use by people with autism; (1) the socio-spatial distance that online communication facilitates, and (2) the preference for visual communication methods and the visual acuity suggested as common to people with autism (Grandin 2006a; Grandin 2009b; Hellendoorn *et al.* 2014; Preis 2006; Rayner, Denholm & Sigafoos 2009). Computer-based activities now afford individuals previously unable or unwilling to connect, greater opportunity to do so. Researchers also have been able to use such technological methods to gain a greater understanding of the lived experiences of autism, in both the capacity of observational, self-advocacy research and for direct communication.

> The Internet is shown to be an appropriate, accommodating medium for those on the spectrum, given characteristic preferences for communication at a socio-spatial distance. The Internet has potential implications for AS [Asperger's Syndrome] social exclusion/inclusion, and hopes expressed in AS writings are high; one author claims that "[t]he impact of the Internet on autistics may one day be compared to the spread of sign language among the deaf" (Singer 1999: 67). (Davidson 2008, p. 791)

Because people with autism seem to prefer visual over verbal communication, visually based investigations are favoured in autism research (Davidson 2008; Hill 2014; Newman, Cashin & Waters 2010; Rayner, Denholm & Sigafoos 2009). Newman, Cashin and Waters (2010) suggest that hermeneutic phenomenological approaches need to include visual support. Using visual aids will 'promote participant engagement and access the eidetic memory of a participant with autism, so as to elicit concrete descriptors of an experience' (Newman, Cashin & Waters 2010, p. 265). By incorporating visual methods into a 'circular interpretative process involving the narratives of those being studied', Newman, Cashin and Waters (2010) contend that researchers will be able to communicate and engage more effectively with individuals with different spectrum experience and therefore elicit richer detail. Because visual images have the ability to transform abstract concepts and memory recall into 'concrete tellings' there is increased opportunity for the researcher to gain greater depth of understanding of 'participants' way of being in the world' (Newman, Cashin & Waters 2010, p. 270).

Hill (2014) uses visual methods in the form of photo elicitation to explore experiences of high school children with autism. Owen *et al.* (2016) use photo elicitation with students in higher education to investigate built environment support. Hill (2014, p. 79) describes her research as 'Interpretative Phenomenological Analysis … chosen to allow for the representation of different realities, whilst also searching for shared themes'. Hill's expressed purpose was to use photographs as a focal point for discussions in an effort to elicit the subjective meaning from each participant. The photos also effectively shifted unwanted focus away from the participant and privileged their voice above that of the researcher. Owen *et al.* (2016, p. 45) cite similar purpose, also recommending the method because of its convenience and minimal intrusion into participant's lives.

For this research visual methods are used as part of the effort to unlock personal stories. They are not used in isolation. Although visual acuity and/or preference is proposed to be common for people with autism, reliance on one form of communication risks the possibility of alienating some people. As articulated in previous discussion, a principal argument of this thesis is the actuality of diversity and individuality within the identifications of autism. In this research study therefore, a suite of approaches offering alternative methods as communication options was provided to give participants choice and to maximise engagement possibilities. Those methods are detailed in the following chapter.

The stories presented in chapters 5, 6, and 7 are not a collective of thematic and spectrum-representative responses, but a series of subjective tellings. Each telling is peculiar. It is intended that the stories presented contribute to understandings of how the built environment impacts the geographies of five individuals with autism. With individual stories voiced and alternate perspectives evidenced, epistemological foundations can then be teased out. It is an interpretivist approach that is, as Cousin (2009, p. 7) describes, embedded with a 'perspective that foregrounds the search for meanings', and the meanings are individual and subjective. It is the position of this research that it is not justifiable to simply observe and document the behaviours of the participants within their given contexts, but rather, it is critical to understand and embrace the experiences of people, to encourage explanation of what it means and how it feels to be located in a given space at a given time.

4.4 The built environment, urban design and public space - multiple voices

4.4.1. From the top down

Urban design and its related/integrated disciplines dedicated to the development of the built environment, such as architecture, landscape architecture, engineering, property development, and city planning, are creative and spatially-based industries. The processes and practices undertaken by these disciplines are objective (practical and applied) and subjective (operating in the space of design and creativity) but the judgement of the resulting design success and quality are predicated on highly subjective grounds. The 'mongrel discipline' of urban design described by Carmona (2014b, pp. 2-3)— discussed in section 2.3—is significantly more complex. The inclusion of 'sociology, anthropology, psychology, political science, economics, ecological, physical and health sciences, urban geography, and the arts,' expands the grounds for judgement of success and quality to subjectivist—into areas that are comprehensively physiological and neurological. From this perspective, it is recognised that urban design has significant impact on our being and on our way of being in the world.

Shaping the built environment is therefore the business of many concerns. I restate a question posed in section 2.3.1; how is that collective determining what is right, just, valued, and good for the breadth and depth of an urban population? There is no singular point of truth, only multiple points of influence. I argue that it is the epistemological foundations of the urban design process and collective that require updating to include a broader, more accurate and more holistic perspective of the human condition. Like the advice of Sinclair about the condition of autism, the urban design collective needs to be coloured. It requires the influence of an all-encompassing and

infiltrating colour, one that recognises difference as part of the spectrum of normal.

The process of urban design includes the shaping of public spaces by (1) public design and authority, (2) private development with civic guidance and approval, or (3) neglect, as urban leftover space that has not been designated purpose by (1) or (2). The built form that defines public places and spaces is determined by the creative shapers who are influenced, guided and persuaded by the multiplicity of affiliate disciplines that have business in the process. Their constructions are guided by personal and advisory decision-making, and broadly by the prevailing ideology of built environment design processes (Imrie & Street 2009). I discussed the politics entangled in the shaping and the provision of access to public space and in section 2.4.2, I suggested a shift in the objective and focus of urban shapers from 'the provision of *public space* and all of its traditional socio-political encumbrances, to a more contemporary, all-inclusive provision of *shared urban space'*.

Considering research methodology for *shared urban spaces* can also contribute to an unloading of the socio-political impediments and influences inherent in the process, including those tied up with the colonial perspectives discussed in section 4.3 above. Traditional methodological approaches are heavily tied to governance and regulatory practices (Imrie & Street 2009). The creative disciplines that contribute to urban design are primarily spatial and political in nature. Spatial disciplines have tendency toward scientific practice, and the political toward governance, hierarchy and control, and both are subject to choice and decision-making, and to the verification and testing of qualities (Biddulph 2012, p. 2; Imrie & Street 2009).

Both assistive and regulatory codes that govern building and design practices base their guidelines and restrictions on statistical occurrence and best-

practice models that are imposed and operated within hierarchical frameworks. Frameworks, like paradigms, are replete with unquestioned assumptions. While frameworks can simplify and streamline the complexities of the 'mongrel' they can also conceal agendas and blinker their users. Biddulph (2012) suggests that urban design research should be thought of as a dualistic pursuit, one based in the social sciences that addresses the applied, practical and creative, and the other based in the arts and humanities that addresses its supporting knowledge. Imrie and Street (2009, p. 2507), with focus on the practices of architecture as a preeminent contributor to built environment production, recommend increased exploration into the 'interrelationships between regulation and the design and production of urban space', noting a current 'lacuna in knowledge'. Ben-Joseph (2009) discussing past detrimental impacts of the codification of the built environment, recommends new approaches that include versatility, experimentation, discretion, the harnessing new information through technology, increased co-operation of public and private entities, and the involvement of communities to establish directions for local context. The fault of past practices Ben-Joseph notes is 'when such codes overstep their bounds and lose grounding' and 'because we have failed to be receptive to their negative impacts (2009, p. 2701).

Carmona (2009, pp. 2643 - 2644) describes the creation of the built environment as a 'collective endeavour' with each component motivated toward an 'aesthetic, economic, social, environmental or functional' outcome. The collective Carmona suggests, can be abridged into three 'tyrannies' of power relationship—creative, market driven and regulatory—leaving the community with only indirect power 'through the right to complain to those with regulatory authority.' Carmona (2009, p. 2665) recommends that the activity of place-making will benefit from a

collaboration of design coding that will 'force the creators of the built environment to recognise a collective and holistic endeavour'.

With recognition that these noted contemporary pursuits and suggestions of best practice are only a small sampling of current discourse, I propose there is common default to the scientific side of built environment research and production—to the place where complexities are simplified and streamlined into manageable portions. Filling gaps in built environment research, recognising past mistakes, identifying power relationships, and combining forces to investigate, design, and implement more holistic approaches to the formation of urban spaces can only improve outcomes. Of critical concern, however, is the motivation and the capacity to inform and update the socio-cultural norms inherent in those processes. It is the embedded language and the 'colonial' approach that also need to be shifted. If such work is left to community voices, which Carmona describes as having only residual and indirect power, then the prospect for change is uncertain; voices are diluted and the ability to reach all components of the collective is challenged.

4.4.2. From the bottom up

A collaborative and holistic endeavour to provide more inclusive urban public spaces requires understanding of the variables, the diversity, and the subjective nature of human use and habitation. While urban thinkers continue to employ elements of quantifiable reasoning there is widespread acceptance of concepts that focus on people-centred design. Alongside social and disability rights activism there occurred a significant qualitative revolution in built environment investigative methodologies. In this section I explore a small but significant slice of this revolution that forms part of the evolution toward more holistic urban design approaches.

In the United States social activism demanded alternative and more holistically considered methods of information gathering. ‘Responding to social and cultural changes in the 1960s and 1970s, many designers saw such issues as environmental waste, resource scarcity in the developing world, urban American poverty, and the struggles of the disabled as potential avenues for an enlightened, progressive design practice’ (Williamson 2012, p. 213). Designers of multiple products began to consult and investigate the user in attempts to justify and legitimise their responses. Writer and activist Jane Jacobs (1961, p. 13) criticised the conventions of city planning practices and called for planners to shed their allegiances to unquestioned orthodox city planning theory, and for designers to look to the streets for evidence and information,

> look closely, and with as little previous expectation as is possible, at the most ordinary scenes and events, and attempt to see what they mean and whether any threads of principle emerge among them.

Although this was not a new idea in philosophical discourse, Jacobs was advocating for phenomenological approaches to be applied to city planning practices. Human experience and situated meaning were being upheld as fundamental urban design components. Jacobs (1961, p. 14) challenged planners to abandon positivist convention, to recognise cities as a problem of ‘organized complexity’, and to seek out the ‘unaverage’ in order to respond in respectful and meaningful ways.

Whyte (1980), urbanist and planner, implemented this challenge. Whyte is credited with originating ideas and research about how public spaces actually worked. In 1969, Whyte conducted a series of studies in the urban spaces of New York that involved direct observation of city life. His studies included

the use of camera, film, and observational note taking, and were a deliberate attempt to extract social, cultural and contextual meaning by observing the activities of urban inhabitants. Whyte's book, *The Social Life of Small Urban Spaces*, is still recognised as an important handbook for urban designers. The hermeneutic methods and principles advocated by Jacobs and Whyte that promoted the user of urban spaces to the position of expert became a new standard. Works by Jacobs and Whyte (1980) continue to be influential in contemporary urban design teachings on people-based methodological theory and practice.

Gehl, also an influential urban design theorist and practitioner, applies the hermeneutic phenomenological ideas and methods of Jacobs and Whyte. Commencing with the publication of *Life between Buildings* in 1971, Gehl has furthered urban design and planning thought into studies that focus on the concept of space and situated meaning, with intent to 'create mutually beneficial relationships between people's quality of life and their built environment' (Gehl Architects 2016). Gehl's studies are composed of methods principally employed to learn about human behaviours within urban spaces, leaving the design of structures and buildings as secondary process. 'Gehl emphasizes that life between buildings is a dimension of architecture that deserves more careful treatment. It is where social interaction and perception, urban recreation, and the sensory experience of city life take place' (Project for Public Spaces 2008).

Methods of research and discovery used by Gehl have extended to become projects heavily weighted in preliminary observation, historical research, contextual meaning and comprehensive consultation with the various interest groups. Gehl and his contemporaries have progressed hermeneutics within their methods to firmly establish primary emphasis upon 'human beings as the starting point' (Gehl, Bundsen Svarre & Risom 2011, p. 8). What continues to

permeate Gehl's approach to research and design methods, however, are vestiges of positivist process.

> Observation and analysis help us understand public life. Throughout our projects, we spend time counting, measuring, and analysing the spaces we are working to improve. Thereby recording the 'life' that occurs in our study areas, as well as the qualities of the surrounding 'space'. (Gehl Architects 2016)

The processes involved in built environment research have positivist foundations that are not easily reformed. Jacobs, Whyte, and Gehl, three of the foremost proponents of urban design thought, have been instrumental in movement away from top down approaches to locate the users of public spaces at the forefront of built environment processes. Their practices however, like those of Alexander and Lynch, are reminiscent of the praxis of the 1960s and 1970s, when design methods approaches, and human behaviour research underscored urban design paradigms.

Continued pressure from bottom-up activists, community-based actors, and professionals with a specific sort of conscience pulls a philosophy of 'people first' to the centre of urban design focus. As disenfranchised groups become more socially and politically evidenced and axiological issues of social inclusion, isolation and justice are brought to the fore, attempts to discover situated, contextual meaning through more constructivist research methods have become the norm for built environment practice. The placemaking movement, for example, with focus on end users and community-based participation and specific focus on the shared spaces of urban environments, has gained strength in the last decade.

> Strengthening the connection between people and the places they share, placemaking refers to a collaborative process by which we can shape our public realm in order to maximize shared value. More than just promoting better urban design, placemaking facilitates creative patterns of use, paying particular attention to the physical, cultural, and social identities that define a place and support its ongoing evolution. (Project for Public Places 2009)

Finding new ways to encourage and activate previously silenced voices through ethnographic procedure has evolved and assisted with more informed decision-making and with the formation of more inclusive spaces. Targeted, participatory qualitative urban design research can continue this trend by giving voice to the silenced, broadening and enlightening the epistemologies of the 'mongrel.' As Oliver (2010, p. 547) states, despite influences on 'mainstream sociology and social education and policy … the need for meaningful inclusion is more urgent than ever and cannot be dependent on the work of a few key individuals for its success'.

For this research I draw some benefit from the act of changing a small part of the urban design language—moving away from the term *public space* to one of *shared urban space.*

4.5 Tailoring qualitative mixed methods

The key concern of this research is that experiences of space and built form are shaped by and shape our world view, by our own realities and, if the broader built environment is shaped by those with common cognitive and sensory mechanisms, then I ask, what are the experiences of those with atypical cognitive and sensory function within shared urban spaces? Building on the research by Baumers and Heylighen (2010; 2010), exploring the unique

way that people with autism view the world, this work exposes some of the manifestations of those mechanisms and provides some insight into their substance and foundation.

This research cannot be satisfied by means of any quantifiable suggestion. For this reason, the search for patterns or trends of behaviour in the built environment, identified as common to autism, have been given little consideration. Simply observing an action or reaction and not reaching beyond it to ask why or attempting to understand context or the individual meaning extracted from the spaces and structures encountered, is contradictory to the primary objective of the research. The stimulation of subjective interpretation to gain a better and more holistic understanding of the experiences of people with autism in public space is primary. Because these experiences characteristically vary from a norm, they incorporate a level of complexity that is neither easily communicated nor easily understood. Potential differences in sensory and cognitive processes and how these may alter experiences of the built environment are the foundation for the inquiry, therefore, methods that allow, encourage, and respect these processes are essential.

Likewise, this study of experience in shared urban spaces seeks to stimulate contemplation of the primary and motivating forces that inform design processes and does so through reflection on individual tellings. Participant stories that make comment on the layout of a café for example, are not analysed purely for their subjective commentary on the design of the space, but for their commentary on the forces driving the decision-making that established them, and of the decision-making of the participant who chose to be there.

The methods chosen are an attempt to minimise the weaknesses inherent in qualitative research procedure, those that exist in my own 'unquestioned assumptions.' They provide a mixture of ways in which each participant can express their personal interpretations with minimal overbearing influence. To explore how space is inhabited, this study requires an approach that considers experiences of access, navigation and occupation holistically. It requires a depth of understanding that can only be gained through participatory methods. Importantly, the *researched* needed be positioned as experts in their own lives, and the *researcher* as someone to be educated about their experiences.

The first two components of the research question—lived experience in public space and the everyday geographies of individuals—suggest methods consistent with the study of human spatial and social geographies such as interview, observation, survey, mapping, and photography (Alexander, Ishikawa & Silverstein 1977; Edwards & Griffin 2013; Gehl & Koch 1987; Jacobs 1961; Lynch 1981; Watson 2006; Whyte 1980). Then, the involvement of people on the autism spectrum requires methods proven to be both sympathetic and flexible. Recent participatory studies that either directly focus on people with autism, or on those with intellectual disabilities, include compilations of autobiographical information, observation, structured and semi-structured interviewing, and varying procedures that are visually based (Baumers, Stijn & Heylighen, Ann 2010; Davidson 2010; Davidson & Smith 2009; Griffith *et al.* 2012; Hill 2014; Kinnaer, Baumers & Heylighen 2016; MacLeod, Lewis & Robertson 2013; Madriaga 2010; Newman, Cashin & Waters 2010; Owen *et al.* 2016).

The amalgamation of the two areas of investigation is not new. The evolution and drive for more socially based, disability-based, user-informed research has encouraged exploration into new ways to highlight and capture true lived

experiences. In the context of the built environment and autism there is increasing academic discourse that seeks to understand, and in some cases provide answers, for ways to improve access and accommodation (Baumers, S. & Heylighen, A. 2010; Bertilsdotter, Brownlow & O'Dell 2013; Hill 2014; Imrie 2000b; Madriaga 2010; Newman, Cashin & Waters 2010; Owen & McCann 2013; Wiesel, Bigby & Carling-Jenkins 2013).

Using surveys, environmental interventions, observation, and literature reviews, Mostafa (2008, 2014) first investigated and then provided a framework for architectural design guidelines for autistic individuals to be used within buildings. Using self-directed photography and semi-structured interviews, Owen and McCann (2013) investigated the experiences of families caring for children with autism in their homes, and in a further study (2016) examined support for students with autism in higher education. Hill (2014) using photo elicitation explored the lived experience of students in a mainstream school, and though autobiographical research Baumers and Heylighen (2010; 2010) examined evidence of 'the diversity of people's interaction with the designed environment'. Kinnaer, Baumers, and Heylighen (2014) interviewed people with autism to investigate 'what an autism-friendly living environment could be', and Baumers and Heylighen (2015) analysed the documents provided by an individual with autism to 'capture' his experience of designing his own space.

While there is focus on autistic experience of the built environment in all of these studies, there remains an absence of discussion that has primary focus on experience in urban spaces. There is limited investigation into what happens when a person with autism moves outside of the relative security of a contained, possibly tailored, single-purpose space and into a more open, less controlled, multi-purpose, multi-use, shared urban space.

Methods used in the current study (detailed in chapter 5) are designed to capture individual, uninhibited, holistic experiences of shared urban spaces. They are designed to allow those experiences to be collected and conveyed by each individual in ways that are comfortable and unpressured, and in ways that situate—as much as possible—authority and control to the participant. These methods align with other built environment and autism research discussed above. They are combined and formulated with the intention of reducing control and coercion in the pursuit of pertinent responses. The process is strongly influenced by Newman and Cashion's (2010, p. 267) statement:

> Individuals with autism, however, have a cognitive processing style that is not neurotypical and therefore potentially at odds with the epistemological assumption underlying hermeneutic phenomenology that language is integral to understanding experience. For persons with autism, information is processed visually, as opposed to linguistically.

Methods are specifically informed by Hill, Owen, and McCann's (2014, p. 79) use of photo-elicitation, chosen because of their capacity to facilitate and strengthen engagement with research process and 'allow for the representation of different realities'. For this study, reliance is not wholly on visual method, rather, photo-elicitation is included into the suite of alternatives on offer. Methods are also are influenced by the 'auti-biographies' described by Baumers and Heylighen (2010) and Davidson and Smith (2009), which encourage hermeneutic, personal stories and geographies. It is intended that the methods of information gathering allow choice to participants, weaken the researcher/participant power relationship, maximise the authority given to each individual, and allow each participant to determine what information they want to record and how they want to

record it, so that by the time the semi-structured discussion occurs the participant can assume an elevated position as authority armed with specialised information.

Also included in the methods is a new geographical element—Global Position System (GPS) mapping. The GPS mapping option provides an additional layer of visual information to the study. GPS-generated maps provide visual records of paths taken. Compared to photographs, the maps provide a less static, more conceptual representation of a person's movement through space. For this study, personal GPS mapping is an attempt to access a new pathway of communication, to open up experiential discussions that focus on decision-making processes such as wayfinding and navigation, allowing for investigation into the cognitive processes that underlie them. The use, benefits, and limitations of this method are discussed in chapter 5 with specific reference to each participant.

Research methods used are heavily influenced by other autism-based investigations. These autism-specific methods are based in the contemporary qualitative methodologies of hermeneutic phenomenology where preference is given to lived experience and to the meanings derived from the narratives of those experiences. Contemporary urban design methodologies share the same philosophies, attempting to diminish the power paradigms of the colonial past and to negate the position of *other* in the researcher/researched relationship. With intent to gain a better understanding of what type of shared urban space might generate a beneficial relationship for a person with autism, the autism-specific, urban design research agenda of this study puts people first and investigates issues of social inclusion through first-hand accounts of experience in the urban environment.

One initial concern with the designed approach was that the high degree of option and flexibility incorporated into the fieldwork could weaken the overall value of the research project. However, what unfolded is contrary to that concern—the flexibility incorporated was critical to the actual recruitment of participants, and the selection and presentation of those options became instead the beginning of each person's story. In practice the selected methods did flutter on a fine line between ambiguity and burden. On more than one occasion, after having read through the research activity proposal and discussing the activities to be undertaken, I was asked, 'so, where do you want me to go', 'what do you want me to take photos of', 'what do you want me to write about'? These questions required answers, and the answers needed to be succinct, unambiguous, and helpful.

What resonated were my readings on a common characteristic of autism—a need for procedural and direct guidance beyond what is typically assumed adequate. I was asking my participants to explain to me what they were about to do next, and to allocate their own time frames to it. It required anticipation and forward planning and meant a potential disruption to routines that were firmly and necessarily established. What occurred therefore, for some participants, was an anxiety around being left with choice, about being asked to make their own decisions about a series of activities that they were of course, unfamiliar with. In my quest to be flexible, to be accommodating by providing options, and to be non-dictatorial, I had overlooked the possibility that a large degree of flexibility could be confronting, and I had not considered that it might have acted as a deterrent rather than an attraction to recruitment.

While this *intrinsic case study* approach represents only a small sampling of perspectives and suggests a limited research scope, it is intended that it provide rich contextual information and insight into lives not otherwise

exposed. ‘The purpose is not to come to understand some abstract construct or generic phenomenon … The purpose is not theory building’ (Stake 1994, p. 237). The purpose is giving voice, providing an opportunity for people’s experiences to be heard, it is exposure and awareness, and an opportunity for me to listen. In the next chapter of Part 3, *Giving Voice*, I provide detail of the research designed to capture the experiences of five people with autism and I introduce the people who agreed to participate and collaborate in furthering stories of autism and the built environment.

chapter 5

Seeking a Golden Record for Autism

Research Design

If you want to tell the untold stories, if you want to give voice to the voiceless, you've got to find a language. Which goes for film as well as prose, for documentary as well as autobiography. Use the wrong language, and you're dumb and blind.

Salman Rushdie

(https://izquotes.com/quote/332777)

5.1. Seeking a Golden Record for Autism

It cannot be said that people on the Autism spectrum are voiceless, but it can be said that a dissimilar voice is hard to hear when your hearing is tuned to a different frequency. *Giving voice to the voiceless* is less about allowing or encouraging people to speak than it is about adjusting your listening to hear. Then, when attuned to the words, the rhythm, syntax, inflection and emphasis of a different voice, superior communication is possible, and a more comprehensive language can be used. This new language will include the ability to hear and the capacity to realise both the spoken and unspoken voices of different experience.

In this chapter I begin to tell the stories of the five people who agreed to share information about their lives. They self-identify as being on the autism spectrum, in the location commonly described as Asperger's. My commitment to this research is to chronicle their built-environment experiences.

Conveying the voices of these five people is an attempt to contribute to the conversation of understanding. This conversation is the medium through which the foundations of communication can be elucidated. It is one attempt to clarify the writing on the casing of the *Golden Record for Autism* in order to gain access to the information inside. As described in the Prologue,

> The individual stories inscribed on this record, revealed in Chapters 5, 6, and 7, are intended to be a part of the advocacy voice, they are attempts to gain better understandings so that the record's protective jacket can be removed, and the contents can be shared.

While the tracks laid down for this *Golden Record for Autism* are individual, the voices are mixed into contextual conversations to form a more unified record of experience. Like any conversation there is no single truth. Myriad factors and circumstances (both at the time of the conversation and at the time of this recording) influence the direction, flow, meaning, emphasis, and the termination point of the words. One comment or statement by a participant will likely inform different contextual threads. Evidence of miscommunication within conversations is as relevant as agreed—or assumed—understandings and the interpretation of all understandings becomes a truth for each individual converser at the termination point of each conversation. What is taken away, the affected meaning, becomes the possession of each individual and will become part of his or her story.

5.2. Research design – scope and intent

The fieldwork that underscores this research is designed to build on the theory, discourse and advocacy presented in preceding chapters by capturing new world-space stories. People with autism consistently reveal their experiences as being different from neurotypical others and evidence suggests that they, like most people who do not fit societal norms, are excluded from shared urban spaces as a consequence. By documenting and exploring the experiences of five people with Asperger's I evidence those differences and expose the factors that contribute to both positive and negative interactions with and within the shared spaces of the built environment. As stated in Chapter 1, *Introduction,* my objective is to seek answers to the following questions:

1. How do people with autism experience ~~public~~ shared urban spaces?
2. How do these experiences influence the everyday geographies of people with autism?

3. How do these experiences support, extend or challenge contemporary urban design theory, policy and practice?

Questions one and two are addressed by means of a fieldwork study that documents the routine experiences of five people. Fieldwork procedure is described in Section 5.3. The purpose of the fieldwork is to provide space and opportunity for participants to arm themselves with *information* that is subsequently shared with me in a one-to-one *discussion*. Here I define *information* to be whatever the participant chooses to share to convey their experiences. *Information* is based upon the suggested fieldwork methods but subject to each person's self-determination. *Discussion*, in the context of qualitative research, is a semi-structured interview that allows flexibility in the flow of topic and conversation and foregrounds me, the researcher, as a 'knowledge-producing participant in the process itself' (Brinkmann 2018, p. 579). Brinkmann (2018, pp. 580-581) describes the semi-structured interview as having four critical components: purpose (to produce knowledge); descriptions (to acquire the interviewee's concrete knowledge); lifeworld (to acquire the phenomenological lived-experience insight of the interviewee); and meaning (to interpret the experiences, actions, and interactions of interviewees). All components bear the weight of ontology, epistemology, power, and ethics that can only be addressed by transparency and acknowledgement that each *discussion* is wholly subjective. Narrative arising from the *discussions* is presented in the following analysis and synthesis chapters (6 and 7) and in the concluding chapter of the thesis.

This work is done to capture each person's expressed relationships with the built environment, to evidence positive and negative interactions, to expose relationships that are intrinsic, routine, and unquestioned and to reveal phenomenological meaning. Participants' personal journals reveal unique insight and provide opportunity for qualitative discussion. The combination

of individual journals allows a search for both commonality and difference of experience. Both individual and combined stories are explored to see whether these unique experiences suggest ways to alter the built environment, or more importantly, ways to alter approaches to the design of the built environment that can contribute to a broadening of inclusion. Simultaneously, discussions with participants reveal my own ontology, which contributes to an informed hermeneutic interpretation.

From the start of the fieldwork, it evolved that the particulars of the researcher-participant interaction, and of the logistics of the research fieldwork itself, were as critical to each person's story as the information netted by the fieldwork. These details and interactions evidenced participant individuality, confirmed the need for flexibility in approach, and revealed my neurotypical positioning. The ways in which each person chose to participate and engaged with the study and me describe their particular experiences of Asperger's and provide authentic and holistic foundations for the revelation of their experiences. The following sections of this chapter detail my initial correspondences with each participant. They are the beginning of each person's story. The progression of each person from a tentative volunteer to a position of confirmed participant in the study enriches the illustration of the person, their individuality and their idiosyncrasies, and I use this information to introduce them.

The following sections detail the methods of access to potential participants, the lengthy process of engagement, the essential offering of flexibility and the tailoring of fieldwork, and describe the challenges experienced throughout this process. Section 5.3 provides a description and explanation of participant research fieldwork as it was designed. Section 5.4 provides description and explanation of the fieldwork as it actually evolved. It explains the recruitment process, introduces the five participants and describes how

each person individually designed their method of participation. Section 5.5 discusses language, highlighting the correlation between broadened understandings, improved language and inclusion. Section 5.6 situates my voice within the realm of neurotypical knowledge and reiterates the need for the evolution of critical thinking lenses so that inclusion can be broadened. Section 5.7 introduces my theory of the *Score of Experience*. It explains and defines my assertion that the experience of urban spaces is like a music score that fills the gaps between buildings and the spaces between people. This section outlines the method used for the delivery of participant stories that follow in chapters 6 and 7.

5.3. Research fieldwork

5.3.1. Overview

Fieldwork was communicated under the title, *Mapping Asperger experiences of public open space: Neurodiversity in the built environment.* It was designed to be participatory and mixed method with emphasis placed on visual methods as a means to unlock personal stories. Five people volunteered to undertake the fieldwork activities—by pseudonym, Andrew, Grace, Patricia, Rob and Stuart. A sixth volunteer was met, and fieldwork equipment was distributed but neither person nor equipment was locatable again. The five volunteers self-identified as having Asperger's and each person selected their own level of participation; they determined the mode of information gathering, timing, procedure, and the degree of involvement with each activity. Opting to undertake all aspects of the fieldwork meant significant commitment for a participant and of the five only two people chose to undertake all methods of information recording. Two others chose only to meet and discuss their experiences, electing not to be involved in any additional form of information gathering.

The details of participation relative to each person are expounded in section 5.4. After recruitment my role was to meet with each person to explain and discuss the purpose of the research and the fieldwork, to provide the necessary equipment, to collect and collate information after they had concluded their fieldwork, then re-present information for discussions, to facilitate and participate in discussions, transcribe recordings, and provide support as required throughout. Between the handover and collection of equipment, participants controlled, and determined the substance and process of their fieldwork.

To provide as much clarity as possible, initial formal communications such as the *Invitation* to participate and the *Fieldwork description and advice sheet* (see Appendix) were presented in pictorial and written formats. Prime consideration was given to minimising ambiguous and academic language and prior to distribution all forms were reviewed and edited by an autism consultant from Learning Services North, Department of Education Tasmania. For me, this process was a lesson in direct and clear communication. Language and directives that I thought straightforward were pointed out to be '*laboriously wordy*' (email 27 July 2015). Words are hard work to process, I was counselled, so '*less is more.*' I culled words and increased imagery and attempted to follow advice to '*balance ethics requirements with ASD friendly presentation.*'

The effectiveness of my communications could only be analysed after I had made connection with volunteers, however even then, I found it difficult to gauge the success rate. It is hard to determine whether people did not volunteer because I had failed to communicate the research fieldwork details adequately. It is possible that the requirement for participation in something unfamiliar and the engagement with a stranger was too much to expect in the

first place. Conversations with the volunteers who ultimately agreed to become participants did however provide some insight, which is discussed in the following sections. The forms and information provided to participants for recruitment and fieldwork advice are included in the Appendix.

Fieldwork was based upon seeking answers to the following question:

How accessible, navigable and habitable are public urban spaces for people on the Autism spectrum, and how do these experiences shape and map out lives?

Gaining first-hand, unfiltered accounts of built-environment experience in order to address this question prescribed who my participants might be and where they might lie on the autism spectrum. Participation in the fieldwork required that people independently enter and occupy shared urban spaces. This requirement considered, members of the targeted participant group were necessarily adults; those for whom the possibility of entering shared urban spaces was not dependent upon the decisions and directions of others and for whom active decision-making was not determined by the presence or the instruction of others. Further, to gain direct and unedited stories my preference was that communications of experiences occur without translation by parent or carer.

Combined, the preferred criteria—independence, fieldwork participation, and direct communication—defined and narrowed the participant group to a small selection of the one-in-sixty population. It delineated a group whose position on the autism spectrum would likely form a cluster and the cluster was likely to be located in the area of high functioning autism or those with a traditional diagnosis of Asperger's Disorder. For this study, this resolution was not problematic. Individual stories were sought, even if they all emanated from a relatively similar spectral locale. The tendency to assume that a group of *people with Autism* or a group of *people with Asperger's* might

experience the built environment in the same way is contrary to the evidenced nature of autism and to the objective of this research. I projected, based on precedent studies (Baumers & Heylighen 2015; Griffith *et al.* 2012; Newman, Cashin & Waters 2010), that individual contextual nuance could shed some light onto difference of experience and in doing so, evidence dynamics not otherwise detectable. As Baumers and Heylighen (2015, p. 13) assert in the case of their documented singular point of view, 'we present this case, characterized by an uncommon situation of designing, in order to give some something to consider in the context of our own experience.'

The volunteers who opted to participate in this research study did so after reviewing and discussing written and pictorial information about the purpose of the study and the fieldwork activities it entailed. My research objective was to have, as much as possible, the participants opt into the study from a position of equality; to see themselves as much a researcher and educator as they were a participant. Evidence from autism-focused ethnographic participatory research, as well as information from self-advocates (described in previous chapters), proposes that this level of ownership can be achieved. As self-advocates, participants will increase and improve my understandings of how the built environment is experienced and I hoped that each person would recognise and assume their voice of authority.

When volunteers realised that they could choose how and how not to engage with the fieldwork anxieties lessened. By allowing each person to determine the pace and to take the lead in early decision-making they became more definitive about the study and confident about what they had to contribute. Some of the challenges associated with Asperger's meant that particular activities were not feasible for certain people. Rob for example, rarely left home. Flexibility therefore was maximised to minimise anxieties, and the decision to engage in or not to engage in all methods of information

gathering was explained as optional. Informed consent for participation required that each individual tailor the proposed fieldwork activities to their own level of comfort and control. Without this option, I would have lost two or three of the five volunteers, and for the others, participation activity would have lessened. The five volunteers self-tailored the fieldwork by removing or adjusting uncertainties and all eventually agreed to become participants. Each person's personalised fieldwork is detailed in the following section.

5.3.2. Methods design

The fieldwork invitation was distributed through Autism Tasmania's networks and via people associated directly with autism networking groups in Tasmania such as the Department of Education's Learning Services organisations. The process itself was lengthy and personally challenging. It was necessary that I rely upon others to promote my research, to extend explanations, clarify where I had been unclear, and generally to encourage participation. In section 5.4, I discuss this aspect of the recruitment process and explain how recruitment unfolded, how each person responded to fieldwork activities and equipment, and how they each determined to complete the fieldwork. This section explains how each of the volunteers transformed into a co-researcher.

After receiving an initial response from a prospective participant, I forwarded information detailing the study via email—which proved to be the preferred method of contact for all participants. As well as explanatory and logistical information, the *Information Sheet* (see Appendix) describes the fieldwork process as follows:

1. Fieldwork: We will give you a GPS device that you can carry with you so you can record where you go when you leave your

house each day for seven days. It can be turned on and off when you choose. We will also give you a digital camera to take photos and a diary to write notes about the things you see and a digital voice recorder to record your comments if you wish to. (If you do not want to use a GPS you can still be in the study)

2. Meeting: We will meet for a discussion to talk about the GPS maps and photos so you can explain your experiences to the researchers. We would like to record the discussion (just your voice) so that we are able to remember everything you tell us.

The progression of engagement required response from each participant and the time frames for this process were often lengthy. The Information Sheet included the statements, '*You do not have to participate just because you have been given this information sheet. You can choose to do the research if you want to.*' These statements were particularly important for people with Asperger's for whom deciding to withdraw after initiating contact could cause anxiety, with the decision falling into a very black-and-white assessment of right and wrong. The potential for triggering anxieties meant that it was necessary to await a response and give people 'space' for their decision-making to avoid applying what might be experienced as excessive pressure. Fortunately, five people responded and agreed to meet to progress discussions about participating in the fieldwork. All ensuing correspondences were direct.

In general terms participants were asked to record their experiences in public urban spaces for seven days. The days did not have to be consecutive, but it was requested that the seven days occur within a two-week time frame. Records could be made by taking photographs, writing diary notes, voice recording and by GPS tracking. Participants were asked to record their every-

day movements rather than create experiences that were outside of their normal routine. A camera, hand-held GPS device, digital voice recorder, notebook and USB flash drive were provided. Once established as a participant, the fieldwork sequence progressed through the following events.

1. An introductory meeting to discuss the purpose and the details of the fieldwork, answer questions, discuss how to use the camera, GPS and digital voice recorder, to distribute equipment and obtain written consent.

Each person determined the meeting location. It was necessary and especially critical to this first meeting that people were in a place of comfort, firstly to begin the handover of ownership and control of the fieldwork and secondly to maximise communication and understandings. The challenge for me at this meeting was to determine whether all the necessary information had been adequately and clearly delivered to the participant while being sensitive to any signs of anxiety caused by the discussion or the proposed fieldwork. For those choosing to record their experiences I provided all equipment and copies of fieldwork information forms in a brightly coloured box. I intended the box to allow for easy handling of all items as well as assist as an organising tool and as a visual prompt for fieldwork activity. The box could simply be handed back when finished. Forms included a pictorially supplemented advice sheet that outlined the requested fieldwork activities and made some suggestions about what they might entail, a form detailing how to use the equipment, forms with questions to prompt activity or commentary, directions on what to do when finished and an explanation of what would occur in the semi-structured discussion to follow. Information also included advice on the right to withdraw at any time.

2. Participant fieldwork, which involved recording seven days of being in or moving through public spaces and could include taking photos, recording daily movements with the GPS device, writing or recording observations and comments.

Each person determined their level of engagement in fieldwork activities. For the four people who initially elected to participate beyond a recorded discussion, a nominal date for completion of the fieldwork—two to three weeks from the introductory meeting—had been agreed. On the agreed day I sent an email to ask how things were progressing. This exchange allowed for the sharing of any problems or concerns and for the establishment of the next meeting for equipment and information collection. The intent with this hands-off fieldwork process was to allow people a high level of autonomy. The risk was that people did not feel supported enough.

3. Equipment and information collection which was again arranged at a time and location determined by each person.

One person elected to email all information and for the other two who completed the fieldwork this meet was a brief exchange. One person opted not to do any activity, so this meeting was unnecessary. One camera had stopped working and this meant that the photos also stopped.

4. Assembly of each participant's written and recorded fieldwork information: photos and GPS tracks were printed, and all written material was left in the manner in which it was provided. Garmin BaseCamp software was used to read and organise GPS output. For the purposes of the subsequent one-to-one discussions, information such as place names and mapping coordinates were left on the BaseCamp

printouts. From each person's combined information, I made a list of notes and questions for use in the discussion.

The preview of each person's fieldwork information allowed me to gain an insight into his or her seven days of activity. It gave me an opportunity to reflect on the stories being told and to consider how discussion points might be integrated effectively and respectfully into the conversation. Importantly also, the act of independently previewing each person's story captured my ontological and epistemological perspectives. On reviewing information, I assumed, judged, deciphered, interpreted, connected and formulated perspectives and understandings of what each person had presented. This positioning could be compared with the voice of each person as they explained their experiences to me.

With the two sets of GPS tracks that were provided I spent some time reviewing options for the extraction and presentation of meaningful spatial and diagrammatic information. This technology did provide an additional item for discussions and it also allowed people to view themselves in a more global rather than personal context. From that perspective, therefore, use of the GPS device was not inconsequential. It did not, however, contribute a significant level of navigational contextual information to the fieldwork study and I now consider the GPS device to be misaligned with the intent of this particular research study.

5. One-to-one discussions at a location selected by each participant: discussion lengths were notified as approximately half an hour and each discussion was voice-recorded. All discussion information was presented in written and pictorial format.

The intention with discussion arrangements was to transfer control to each participant. For the discussion, four of the five participants chose a public place and the fifth elected to be at home. For the three people who completed fieldwork activities, control was readily adopted; the information on the table was theirs. Diagnostic Criteria of DSM-5, *Neurodevelopmental Disorders* (American Psychiatric Association 2013b), cites 'abnormalities in eye contact' and 'atypical use of eye contact (relative to cultural norms)' as diagnostic criteria for autism. Therefore, positioning the pictorial and written information as the focus for discussions shifted emphasis from the physical person onto inanimate objects. It redirected and relieved the pressure of extended visual contact for the person whose experiences were under scrutiny. What this strategy meant for individuals is described in section 5.4.

For the two who did not engage in fieldwork activities, where conversation had no visual prompt, there were moments of hesitation requiring that I generated and directed discussion, which was something I had hoped to avoid. This did not however weaken conversations and does not diminish contributions. It could be said that the absence of focus on objects on the table caused conversations to take on more philosophical and advisory tones and that it demanded a more holistic analysis of personal environmental experience. While this did occur, I suggest that these theoretical contributions were more personality driven rather than a consequence of the absence of imagery and written words. Also, and equally, the presence of fieldwork objects did not detract from the richness of a person's story nor their tendency to provide philosophical perspective. As previously described, the provision of options to engage with the fieldwork in different ways accommodated individual preferences and allowed for contributions that may have otherwise been unattainable.

6. Transcription of voice recordings: individual recordings were transcribed verbatim. Transcription documents were then emailed to each person for review and comment

What eventuated because of the protracted recruitment process was an almost sequential participant engagement process. My first participant meeting was with Andrew in December of 2015 and the last discussion was with Patricia in August of 2016. I endeavoured to return transcripts two weeks after a discussion and did not receive any requests from participants for any alteration or deletion.

5.3.3. Reflexive comment

The participant recruitment experience confronted me with an ethical challenge. This study is based upon the suggestion that environmental experiences are often different for people with autism. What this suggestion means for participants is therefore an initial agreement or acknowledgement of difference. By simply opting into the study a person is accepting the suggestion that they are different and, furthermore, they are agreeing to expose their self by revealing those differences. I asked people to rouse feelings and experiences that—on reaching adulthood— had often been long suppressed. On initial contact with most participants I was told that the environment was not problematic and ensuing correspondences reinforced this perspective as a foregrounded truth. The uneasiness I began to feel was a concern about unsettling the comfortable world-spaces that my participants had fought harder than most people to establish, that is, I was concerned about disturbing those backgrounded truths.

By the time we are independent adults, the management of our environmental experiences includes constructions of safety. To the best of

our individual abilities we learn to protect ourselves from harm by avoidance, by backgrounding unfavourable, harmful or painful experiences and by minimising exposure to them. On reaching adulthood we have learned about our selves, our strengths, weaknesses, capacities and incapacities and we have organised our lives accordingly. Significantly, what we have done is managed and compartmentalised many behaviours and responses into automatic and unquestioned routines and practices, and it is not until someone or something questions those behaviours that they resurface to confront us again. This resurfacing has the potential to cause discomfort or possibly even harm. At the very least in this particular circumstance, it has the potential to reinforce the characteristics of difference. The fact that these five people had opted to participate however did mean that they were willing to risk some level of exposure.

This fragility of confidence and potential for harm meant that the threshold level of comfort for each participant had to be independently determined. Participants were allowing themselves to be exposed and the degree and aspect of that exposure was relative to the person. Continued participation required my acceptance and sensitivity to what they were willing to offer and to how they chose to engage. For each individual, the point in time and the position in the fieldwork process when this threshold level was exposed varied. The result was that the fieldwork maintained little consistency between individuals. The following sections commence each person's story by describing the thresholds that define each person in the context of this built environment research.

5.4. Seeking contributions to the Golden Record

5.4.1. Recruitment

Contacting people from a 'geographically dispersed community' required the aid of an established network. Participants were approached through Autism Tasmania Incorporated, an organisation focused on education, practical assistance and support (Autism Tasmania 2016). Members engage with Autism Tasmania primarily for friendship, advice, specialised help and encouragement and, while accessing an active community through this organisation was possible, accessing a group or even individuals with advocacy as an agenda was not. As an organisation, Autism Tasmania does seek to generate awareness and improve understandings, and it enthusiastically supports and embraces relatable research, but it does not include an active advocacy group. Membership group objectives do not necessarily extend to effecting change. Therefore, the process of finding people through Autism Tasmania who were willing to share their experiences—and in doing so become self-advocates—met with challenges. Without the organisation's assistance, however, and within the constraints of ascribed ethical research practices, finding participants would have been extremely difficult.

Autism Tasmania provided intermediaries who assisted by introducing the study, legitimising my position as researcher and importantly, by establishing a necessary framework of trust. Significant also was the ability of Autism Tasmania personnel and associates to encourage and foster confidence in the individuals who eventually chose to participate. To these people I am indebted, especially one who allowed me to visit her Asperger's Group meetings, introduce my research and invite people to participate. I was a stranger, someone potentially compromising a status quo, someone who had

the potential to elevate the very differences that people were coming together to moderate. By having a familiar and trusted person introduce the idea of my research, and by observing and following her lead, I was able to talk freely with two established Asperger groups. My language was occasionally corrected to remove ambiguity and clarified by extending and redirecting explanations. My Autism Tasmania interpreter was also able to exemplify and personalise the objectives of the research. My presence at these meetings was an introductory recruitment activity and not an established part of the information collection process and for this reason I did not formally record them. Discussions however, in this safe environment, were rich in experiential detail. What transpired suggests that future research might simply commence with an organised group discussion rather than a search for individuals.

The five volunteers who chose to participate emerged through this connection. All five volunteers initially commented that they had little to offer to the study and all required significant encouragement and support with their decision to be involved. Another intermediary from the *Autism Tasmania Information Team* noted of one potential participant,

> *[Rob] is probably a bit nervous, but sincere in his belief that he wouldn't have much to contribute as a participant, because of his literal interpretation of the research and his infrequent use of public spaces. I hope that with some further discussions with you he may realise that his tendency to NOT use public spaces is useful too! I know he has a lot to contribute to so many things.*
> (email correspondence Feb 8, 2016)

Recruitment therefore was a lengthy and necessarily gentle process that resulted in a shift in the methodological intentions of the study toward the

extreme of flexibility. Engaging with people with autism did not prove to be difficult because of differences in understandings, interpretations or—after receiving assistance from Autism Tasmania—even access. Rather, difficulties were attributable to the self-confidence of individuals and their perceived value as participants but mostly, it was attributable to the safeguarded, sometimes secluded, and sometimes solitary lives that they were used to inhabiting.

5.4.2. Contributors

The participants who provided insight into their daily experiences were, by pseudonym Andrew, Grace, Patricia, Rob and Stuart. Ordering of participants here and in the following chapters where not directed by context has only alphabetical purpose.

Andrew

Living on the edge is how my first participant described his life. Andrew is in his mid-fifties; ostensibly a worldly, confident, and capable person previously employed in IT-based positions—a self-described IT expert. Once married and a father, Andrew spends some of his time job seeking but is primarily engaged as a full-time live in carer for his aging parents, consistently describing his employment as a thankless occupation; '*unacknowledged … I mow, brush cut and make firewood; but mostly sit on my butt waiting until they need a driver*' (email September 2017). When not attending to his parents Andrew noted that he spends a great deal of time in his room occupied with the trappings of his computer. He wears a phone audio device hooked around his ear when out of the house and away from his parents (and possibly when indoors), making him immediately contactable. I couldn't help but

picture Andrew aboard the Geek Cruise in 2000, part of the digital native tribe described by Silberman (2015, p. 3), happily and enthusiastically conversing with other IT-experts who operated 'on the same frequency'.

Andrew's level of comfort with the technological aspects of the study were reassuring. There was consolation in the fact that what I had proposed as a means for collecting information from and with people did not appear to be too demanding. Andrew had previously used a hand held GPS and had a greater understanding than I did of the workings and uses of the data they return. Knowing that he was my first participant, he described himself as the '*lab rat*' stating that he was happy to be one and hoping that what he had to offer would be useful to others in the study. However, beyond the technological transactions it was progressively revealed that the words and imagery of my fieldwork descriptions and directives were not embraced as easily. Although he had indicated that my explanations were sound and that he knew how to proceed, Andrew, after commencement, had not been able to make sense of my fieldwork assistance guidelines.

> I didn't have a clue all along exactly what you were looking for, so I had to try and improvise it … I just couldn't do anything until I figured out how, and it sort of all came together at the last minute. Aha, this is how I can do it! (interview Jan. 2016)

Andrew, therefore, after a period of frustration, formulated his own guidelines. This outcome was confronting. The first participant response to my research methods was that I had not been prescriptive enough, that I had not provided adequate direction, description, advice, example or pro forma. Although I had offered some guidance, what I had provided in the way of

introducing and describing the fieldwork component of my research, had proven to be inadequate. I had placed my first invested participant into an uncomfortable and confused situation needing additional or alternative support. As a reaction to his statement, I began to re-think the structure of the fieldwork study and the supporting information; I searched for ways to make the methods more methodical and to improve the props so that the remaining participants did not experience the same difficulties. I noted the following in my fieldwork diary, *'I realise that in my drive to be flexible I have probably left too much up to the participant (not good for Asperger's) therefore I may need to establish more structure.'* This reasoning made sense when reflecting on diagnostic discourse; one of the often-noted characteristics of Asperger's is an above average need for structure. However, this reasoning must be abandoned and recognised as logic steeped in both the understandings and rationalisations of neuotypically described autistic experience, and those of my neurotypical brain.

So, Andrew reorganised, or, added further organisation to my participant guidance provisions. My *Daily Fieldwork Notes* guide (see Appendix) proposed loose questions such as, *'is there anything you want to tell the researchers about the places and spaces that you went through today?'*. The wording was an attempt to not be prescriptive and an effort toward encouragement of independent and personal thought and responses. Andrew however required direction. He reformatted and prescribed the guide with the following directives stating, *'The form seemed to work well for me'* (diary Dec. 2015):

0. Date[i]
1. Significant coincidences (just kind seemed interesting)
2. Tasks
3. Location (kinda like home, etc)

4. Good Places
5. Bad places (logical)
6. Notes (more ignored than used I think)
7. Attachments (typically to mention GPS log, relevant date for photo folders)
8. Built environment (describe and its impact)
9. Typical day (Y/N, and details)

[1] It's zero because I didn't think to number it at first, and one was taken.

This structure allowed Andrew to participate. For me however, it was an uncomfortable challenge to my deliberate attempt to be non-prescriptive and flexible. My want to avoid influencing people and their decisions, to decrease the possibility that they would provide me with answers they thought I wanted to hear, had proven too vague for my first participant.

There was of course the possibility that this consequence was specific to Andrew, and because of this I did not alter my approach or methods when engaging with my second participant.

Of the five participants only two were willing to use the GPS device, and of the two, Andrew was the most engaged and least daunted. It was hard to determine whether the three who declined were uncomfortable with the technology, with the time associated with learning how to use it, or with the thought of being tracked by the device. Andrew though seized the opportunity that the GPS device and the fieldwork represented. He viewed the fieldwork as a chance to momentarily free himself from the world-space he was now begrudgingly occupying, and he admitted to thinking about where he might take the GPS device. *'I've got to be careful not to taint the results'* (email Dec. 2015) Andrew stated, after revealing he was keen to include a bushwalk to a favoured but not commonly frequented location into his daily activities. He noted that it would make for interesting tracking and also provide opportunity for him to escape his familial duties. This prospect

presented a conundrum for the study, one that I was hoping to mitigate. Would Andrew's desire to manufacture daily activities outside of his normal routine affect the collection of information I was trying to gather? If Andrew were to actively choose where to venture so that the GPS device was providing 'interesting' data, the environments of choice would be only those of favour and the information returned therefore premeditated, contrived and unbalanced? Or was the actual location of information collection irrelevant?

I propose that Andrew's actions are instead part of his story, a story that developed further in conjunction with other locations and contextual conversations. Andrew was not suggesting that this venture would be in an urban space nor was it a personal *everyday geography,* but his choice to seize an opportunity for solace in a natural environment is a personal and valid response to place that should not be challenged and instead provides insight into his experience of environment.

Grace

'It's busy, but it makes me happy' is how Grace described her life (interview Apr. 2016). She labelled herself as 'just a volunteer and an art student' (interview Apr. 2016); art activities are her hobby of choice and the primary focus of the groups she chooses to belong to. The prospect of using a diary to record her thoughts in words and pictures and having new opportunities to explore were likely what attracted her to participate. Between her art-based activities and regular volunteer work in two charity shops, Grace's days are full, and her independence fortified. Far from the withdrawn children described by Kanner and Asperger (Silberman 2001, p. 2) Grace is adventurous and outgoing, describing herself as having a brain that is 'never resting':

> I always seem to be like the person, always someone who wants to be on the run, my brain always seems to be a bit restless. The funny thing about me is as soon as I get to one place, I just say to myself, grab this book, this and that, go to the librarian and then go home or go to a different shop and then quick look and then go home. (interview Apr. 2016)

Grace chose to meet in a café and was accompanied by her mother. Our email exchanges to arrange this first meeting did not reveal that her mother would be with her and I was uncertain whether she would chaperone and leave or remain. Grace's mother did stay for the duration of our first meeting and also for our second post-fieldwork discussion. This scenario challenged my ideas about the self-determination of my participants, and I was forced to reconcile the implications of having one participant alternatively situated in the context of the study. Did the presence of a carer and chaperone alter the validity of the experiences I was trying to understand?

After meeting Grace, I surmised and appreciated that her mother was there as a safeguard to her daughter, to protect her vulnerability. Grace is in her mid-twenties, an open and trusting individual with a soulful desire to be helpful and an energetic determination to further her experiences in her areas of interest. The fieldwork offered her opportunity to photograph and illustrate her feelings about the environment, things for which Grace has great enthusiasm. Grace's mother was her tempering valve, responsible for her peripheral vision and a cautionary check on her enthusiasm. There were moments when her mother's voice was dominant, and it became obvious that Grace and her mother were united. Grace's voice of experience was tightly entwined with her mother's and, even when alone Grace moved and operated in spaces within her mother's vision. On reflection, I determined that the presence of Grace's mother did not alter the validity of her experiences in the

context of the study because the presence of Grace's mother was her experience. It was therefore a part of her personal and unique, alternative way of being.

The café was an extremely noisy space of concrete, steel and glass with no sound attenuation, a place of constant echo and reverberation of both voices and the activity of the café. It was an environment that I found to be quite audibly uncomfortable. At this introductory meeting Grace's mother advised Grace's diagnosis as Pervasive Developmental Disorder—the 'catch-all diagnosis' of which Autism is a part (American Psychiatric Association 2013a). Grace's mother's advice was that most of Grace's Autism symptoms had lessened by the time she reached adulthood. She explained her daughter's position in regard to the noise in the café, stating that being in the café would not have been tolerable when she was younger, that Grace had learned to cope with noise as she got older and that she could now mostly abide it as other people do. It was also explained that Grace's comfort level was increased by her familiarity with the café, although, her mother advised, she could probably not stay for long.

This declaration of Grace's disciplined status was a provocation that reinforced my motivations. To have access to the café it was necessary for Grace to *learn how to cope* and Grace's mother described how her coping was achieved by means of a tolerance-training regime, a form of environmental conditioning. I later learned that Grace carries earplugs wherever she goes to increase her access and inclusion into such spaces, into the noisy shared urban places that exceed the limitations of her tolerance trainings.

Grace learned to navigate her environment to supplement her interests and her restlessness. She received dedicated training in the use of the public bus system. As a non-driver this skill provides a much needed and appreciated

outlet for both Grace and her mother, and as her mother described, it is a necessary part of a secure future for her daughter when she will no longer be there to support her. While Grace embraced the idea of the fieldwork and was excited about the creative components, she declined both the GPS device and the voice recorder. Grace was unfamiliar with their use and generally less IT disposed. Of the five participants Grace was the least computer active and I wondered if this was due to a protective motherly action or simply a lack of interest. She did have her own email address and it was her preferred method for communication with me, but she had noted during our early correspondences that her access to it was limited.

Grace's refusal of the digital voice recorder was not unlike the other four participants and I surmise not unlike most other people—it is not a common use device. Grace's reaction to the GPS device however was significant; my diary notes the following:

> Grace did not want to use the GPS, saying that she was not familiar with it. Perhaps because it was something new or maybe the idea of being tracked was concerning. Regardless, she was quite adverse to it and quite unwilling to discuss the possibility of using it. Her body language during this exchange was noticeable. When I reached for the GPS, which was boxed, she sat stiffly upright in her chair and as I removed the GPS from the box and handed it in her direction her rigidity increased. My intention was to familiarise her with what it looked like, with its small and innocuous appearance. She did not take the GPS from my hand. Instead, she shifted her body in the opposite direction, turned her head away and said sternly, "No, I don't want to use it." I quickly put it back in its box and out of sight – I believe it actually made her physically uncomfortable.

The email correspondences that lead to both this first meeting and those following occurred over several weeks and several exchanges. Eight emails and eleven phone text messages were needed to establish a time for the collection of fieldwork equipment. Exchanges addressed one topic at a time and further tested my ability to remove ambiguity from my dialogue. Grace's communications were direct, and her reading of my words was literal. Her understanding of what was asked of her was hindered only by my inability to be concise and to remove any extraneous information from fieldwork descriptions. What also became evident at this first meeting was that Grace would strive to do exactly what was asked of her and possibly do this to her own detriment. To maintain her comfort level, I confirmed back to her what her fieldwork would entail, and removed all suggestion of anything beyond it. I left our first meeting with my own level of excitement, anticipating a diary full of expressive illustrations, so I was surprised when I received a diary with none.

In contrast to Andrew's need for a structure that enabled him to formulate his responses, Grace's creativity was likely stifled by the control embedded in the activity guidelines. Being a person who will dutifully obey direction and likely not deviate, Grace followed the guidelines literally and provided back to me exactly what was proposed by the guiding information. She did not augment her responses nor deviate from the suggestions. My verbal offering that her responses could be presented in an alternative manner and that the methods of information collection could vary was overshadowed by the written guidelines that Grace took home with her. On reflection, after establishing how she wanted to proceed, the tailoring of the fieldwork should have extended to a complete re-write of the guidelines specifically for Grace. This reflection is in no way a suggestion that Grace's contribution was less than any other but it does suggest where improvement might be made with future research; if methods are fully tailored to the individual through mutual

agreement, all superfluous information removed and all guidelines re-written prior to activities commencing, the material returned might provide even richer detail.

Patricia

It was not until later in life, after discovering on-line communities and reading an article on Asperger's, that Patricia realised her general feeling of feeling 'like an outsider' might have an explanation. Traits such as difficulties forming relationships, differences in the types of things that did and did not come easily, the inability to engage in small-talk, difficulty with looking at people's faces when conversing, the constant feeling that the wiring or chemical balance of her brain were different, all aligned with the autobiographical descriptions of Asperger's she found on-line. Previous professional diagnoses and treatments for anxiety and depression were neither fitting nor relieving but, Patricia described, surrounding herself with people who understood Asperger's did.

Patricia is a published author and avid writer. She publishes a blog of photographs, essays, journal entries and research data. Her blog is an articulate, broad and illustrative collection of her interests, both by account and anecdote, the type of information that will some day help fill missing parts of our anthropological history. It is in these writings that I learned the details of her Asperger's diagnosis described above, something that Patricia, unlike others, did not discuss or disclose in any of her introductory correspondences or fieldwork information sharing. It was surprising to see these personal entries, as the majority of her publications are objectively presented, impersonal and impartial, and while these diagnosis discussions are more intimate, they maintain an editorial style authorship. They describe Patricia's experience in the context of medical misdiagnosis and social

stereotype, making comment on the uncertainties and inaccuracies that dominate current understandings and discourse, things that had affected the decisions and pathways of her life.

Patricia is the second participant who elected to undertake all proposed fieldwork activities. We met in a café of her choosing—unlike Grace's choice, one of more traditional design, with reasonable sound attenuation. I entered the space on time, scanned the room locating a person who appeared anxious, constantly flicking eyes in the direction of the entry and away again. (Although this description seems presumptuous, others in the room were occupied and otherwise distracted.) After introductions and a quickly withdrawn and timid handshake, I sat in the seat beside her at a small distance, assuming that a direct-facing position would be confronting. Our exchange continued in this way and Patricia's continued eye flicking confirmed that I was appropriately located. As this transaction progressed, I recognised my own reliance upon facial expression for the confirmation of understandings beyond the words being spoken. I was using my short glances as desperate attempts to gain confidence that the information I was imparting was being understood, but it was her words that I needed to rely on. I could not capture her countenance long enough to determine any expressions of understanding or otherwise.

Although she was unfamiliar with the technology, Patricia agreed to use the GPS device and appeared to quickly understand its operation. The camera required no detailed discussion with Patricia opting to use the loaned, basic digital rather than her own more sophisticated digital SLR, noting that the loaned camera was smaller and would be more easily transported and discreet in public places. My information forms had been only vaguely helpful to Patricia also. I was confronted again with the question of what activity was expected. Patricia pointed out my communication shortfalls with direct,

matter-of-fact statements and questions. Our side-by-side pragmatic discussion gave Patricia the information she required, and she left our meeting appearing confident with my fieldwork explanations and her planned activities.

Throughout this meeting Patricia's apparent uneasiness with our interaction did not subside. Neither the increase in her understandings nor moving past personal introductions to moderate familiarity altered her obvious discomfort. The physical proximity required for effective communication appeared to exceed Patricia's comfort level and her desire to leave became increasingly obvious. This discomfort did change during our third and final meeting when discussing her fieldwork. At that meeting Patricia's comfort level visibly altered as the focus shifted more heavily onto the information in front of us. She became more talkative, volunteering information without prompt and, although her descriptions remained very direct and unadorned, they started to resemble the writings of her blog.

I was challenged by Patricia's minimal and unembellished output from the fieldwork. I had allowed the fact that Patricia was a writer to colour my initial expectations of her as participant—something that I should have been both conscious of and careful to avoid. Any expectation that she would adopt an author's interest in a study that was not her own was inappropriate. Patricia's literal interpretation of the study deemed it a quest to find factual answers to questions of successes and failures in the built environment and she was correspondingly literal and dutiful with her returned fieldwork. Patricia answered questions with simple and direct responses providing only a small amount of written detail for each, often answering with a singular yes or no. This was further evidence of my need to prepare guiding questions more carefully.

Of the five participants, Patricia presented the most unemotional position. She did not respond as if she was personally affected, but instead determined built environment componentry to be either useful or not, or to have or not have, a recognisable purpose. Roads for example are not useful because Patricia does not drive, therefore catering to vehicles rather than pedestrians solicits an obvious response; *'get all the cars out of it'* (interview Aug. 2016). Similarly, if a bus shelter did not keep the rain off then it could not be a 'shelter' and was simply and factually deemed by Patricia as a 'stupid' design with no further need for discussion. This characteristic meant that discovering any underlying meaning derived by Patricia from the built environment might be difficult.

What did prove to be a successful component of the research design however, were the methods of engagement. Because Patricia was able to participate by taking photographs, using the GPS device and writing, and because her photographic images became the focus of our discussion, Patricia was able to find her voice. The tangible elements of the fieldwork redirected emphasis, helped to subordinate my presence and importantly, enabled a more uninhibited sharing of Patricia's experiences.

Rob

There were no visual supplements or orchestrated distractions to support my discussion with Rob. As noted previously, Rob was a reluctant participant. Describing himself as someone who did not leave home very often and someone who rarely entered public places, Rob believed that he would have little to contribute. After several emails and a short phone conversation however he agreed to participate by way of discussion only. Initially Rob requested our discussion be a phone conversation but, after learning that we could meet in his living room, he agreed that we could meet in person.

During our phone conversation Rob was very candid about his fears and anxieties stating that he was not sure that he could be comfortable enough to sustain a long conversation and that he may not be able to share any insightful information. To address his concerns, we agreed that he would need only to raise his hand to gesture any feelings of discomfort or distress and that this would be a signal for my departure without any requirement for explanation.

Rob's living room was in his family home where he lived with his parents. His quick glances and rapid sideways head movements at the front door verified that he was uncomfortable with eye contact. He seated himself on one end of the sofa and I seated myself on the other, only slightly turned toward him so that I did not look at him directly. When we both looked ahead our gazes crossed but did not meet. This positioning (like that with Patricia) meant that we could converse without looking at each other for lengths of time. I was very conscious of this arrangement for our full one hour and forty-five minute discussion; there was no indication from Rob that this could change. Rob agreed to use the voice recorder but did not want to see it and requested that I not replay any recordings because he did not want to hear his voice. I placed the recorder on the floor out of sight. A short time later, concerned that it was not picking up our conversation, I asked to move it closer. This Rob allowed—on the condition that it remain out of sight.

Rob was visibly anxious. He explained that since leaving school (he was now in his mid-twenties) he did not have a daily routine and that the lack of structure and obligation affected his ability to be social. He stated that it is the social environment, not the physical that impedes his comfort and he explained how his fear of asking for assistance compounded the problem.

Because there were no fieldwork information disclosures or visual props to refer to, our discussion relied upon the manufacture of topics. This scenario increased the risk of influencing conversation, prioritising subjects, omitting experiences, and pre-determining meanings. Removing adjectives, inflection and subjective content from my language was a challenge so I resolved to submitting nouns such as '*footpaths'*, '*seats'*, '*signs'*, '*park*' with an added, '*can you tell me about these?*' hoping they would take the place of a photo and trigger Rob's subjective response. The lack of visual prop did not prove to be an impediment to conversation, but it did mean often straying into very lengthy off-topic discussions in the areas of Rob's particular interests. He described himself as being obsessive and also having Obsessive Compulsive Disorder, a condition he linked to Asperger's. Moving away from a topic, therefore, and finding another was often awkward and his preference for talking about his obsessions did limit conversation about his experience of the built environment.

For Rob, discussions that focused on his areas of interest appeared instrumental in providing comfort. Allowing the discussion to be somewhat serendipitous helped Rob's nervousness to subside. After a short time he openly shared stories of his life and confidently articulated his experiences, likes and dislikes. At the conclusion of our conversation Rob offered to take photos of some of the places he had spoken—the next time he left home—but this did not eventuate.

Rob in particular heightened my concerns for doing harm through this research. He was clearly sensitive and vulnerable. During our discussion he revealed his constant struggles with anxiety and depression, and his consequent self-isolation. This disclosure made me feel slightly uneasy and very unequipped to handle potential outcomes. Several times I directed conversation away from topics of psychology and from thresholds where

personal exposures appeared to be increasing. I needed to maintain my position as an urban design researcher and contain my purpose to discussing experiences of the built environment. There is conundrum, however, in this position. By asking Rob to describe his experiences, which consist primarily of environmental discomfort, I was also asking him to reveal and confront the things that cause him difficulty and that contribute to his anxieties. It was not possible for Rob to separate and isolate the psychology of his negative experiences and quarantine them for my convenience. How he felt in the built environment is exactly what I set out to explore.

As discussed in section 5.3.3 above, the underlying assumption of this research is that people with Asperger's experience the environment differently. Therefore, the underlying supposition of our discussion was that Rob's interactions and reactions were abnormal. What was possible was that this discussion could reach a level of harm. I was reliant upon Rob being, and being able to be, frank about his comfort level, and upon the advice of the Autism Tasmania contact who believed that his confidence could be improved once he realised, he had something to contribute. He did not raise his hand or cease talking so I stayed for as long as our conversation continued.

Rob did become conversationally relaxed quite early in our discussion, but I left our meeting questioning whether my undertakings were appropriate, asking myself if I could still consider my research justifiable. Was I risking exposing the fears that Rob was constantly and desperately trying to keep at bay and in doing so reinforcing his feelings of difference and further cementing need for exclusion? As with other participants it was not possible to separate or extract social experience from environmental experience, nor was it possible for the participant to extract the emotional from their experience. My conversation with Rob left me with a heightened

understanding of the power of a sculpted environment, of the process of place making and its ramifications as both a conscious and unconscious act of deciding who can and who cannot be included.

Stuart

Several weeks after our first meeting Stuart decided not to engage in any fieldwork activities. He had taken all equipment and did appear enthusiastic about the prospect of sharing his experiences through photography and possibly GPS tracking but in a later correspondence (prompted by a gentle email enquiry about how he was progressing) apologised for not having any '*raw fieldwork data*' (email Jul. 2016) stating that he '*didn't really go for the set fieldwork*' (interview Aug. 2016). Stuart advised that during the four-week interval he kept the study in mind, and he suggested we should still meet to discuss what he had been thinking about; '*I might have some useful thoughts to share with you nonetheless*' he said (email July 2016).

Stuart chose to meet in a café. We sat outside on opposite sides of the table, indirectly opposite to avoid the confrontational gaze. He was apparently anxious, which was evidenced early in our meeting by him suddenly ceasing conversation, stating he was feeling dizzy, and waiting several seconds before resuming. After that, our conversation was comfortable, and Stuart appeared eager to share his thoughts and experiences. At the time of our meeting Stuart was 27. He was diagnosed with Asperger's as a child, worked casually in IT development, lived independently at considerable distance from his family, had spent time in large cities, has a driver's licence, a car, and a university degree. Information Technology was Stuart's second university major after several years of studying psychology, which he described as, '*pretty distressing … it's learning about all the things that can go wrong with*

people' (interview Aug. 2016). He explained his career decision as a directive driven by a narrow set of options.

During the period of our correspondence Stuart's employment ended and he was faced with finding something new. This prospect did not appear to be concerning, rather, he viewed it as an opportunity to restructure his activities so that his '*creative energy*' could be directed toward his hobby—making a comic strip about a boy with Asperger's. He explained that he was responsible for the graphics and the storyline of the comic and that a friend was helping with the text. On several occasions Stuart had also been actively involved in the organisation and tutoring of IT-based gaming competitions and programs, stating that he recognised this activity as an extremely valuable socialisation practise and outlet for people with Asperger's.

As described in the Prologue, Stuart is insightful and articulate and as described above, active and interactive. Like my meeting with Rob, there were no visual props for reference or support during our discussion and this meant that topics were subject to a degree of manufacture. Stuart's four weeks of thinking had provided opportunity for consideration of conversational directions, which he was well equipped to orchestrate and ready to deliver. On several occasions I became aware that he was one step ahead of me, directing and anticipating our conversation, ready to make a point he had previously formulated. Stuart led our discussion with a statement about the environment and the behaviour of people that emulated opinions of both Rob and Andrew. He determined people's behaviour to be the cause of environmental concern, not the design of the environment itself. Stuart's view of making the world a better place was through IT augmentation and high tech assistance; correcting or improving the behaviour of people was something he had determined impossible and dismissed, conversely,

information technology had already improved circumstances and opportunities, and it had unlimited potential to continue to do so.

This aspect of Stuart's outlook resonated with the intimation I had sensed from conversations with other participants. While they held frustrations about the behaviour of others, about the shaping of, and the shape of the built environment, there was an overriding acceptance of being the marginalised 'other' and of having to assume all responsibility for adaptation and tolerance. There was no expectation that the behaviour or attitudes of people, or the shape of places, would change to become more understanding or more accommodating of their differences of experience. This placement of the onus to conform or to exclude one's self from the built environment is a contributing factor to the discriminations addressed in this thesis and is discussed in more detail in the following analysis and discussion chapters.

The end of one topic and the search for another did occasionally affect the flow of my conversation with Stuart, and my attempts to introduce new topics were more often met with academic discourse rather than stories of experience. Stuart did, however, provide insight into his life with Asperger's and he was aware that I needed to be educated about alternative world-spaces. He wanted to be a bridge for the understanding of cognitive differences so that the inscriptions on the casing of the Golden Record that he had previously described might have an improved chance of being interpreted.

5.5. The language of understanding

As noted above, my attempts to keep language direct and to the point when communicating with participants did not always succeed. This process revealed the degree to which language can obfuscate intentions and meanings and how its colloquial use can compound the effect. Even when

cognisant of the possibility of misinterpretation or confusion it can be difficult to be clear and concise, especially when your audience have a tendency toward literal translation. This phenomenon contributes to isolation. In the context of autism, language can be a recognisable symptom and can vary between complete absence, echolalia, and literal interpretation to having above average command or no obvious affect (Edelson 2019). Languages evolve and change with trends and generations; they are socially bound and heavily tied to popular culture. 'Accordingly, language must be seen as not merely reflective but instead as *constitutive* of social life' (Mansvelt J. & Berg L. in Hay 2010, p. 339). If then, an individual has a predisposition to the literal and unembellished use of language and also remains on the socio-cultural periphery, the process of infiltrating and being included into contemporary culture must prove even more difficult. Unless the person, or people, on the other side of the interaction understand how the language needs to be effectively communicated then understandings will be lost, and distances will grow. In parallel—in the context of the built environment—popular and vernacular socio-cultural language is built into the places we construct with an assumption that everyone is going to 'get it,' that everyone is going to ride the wave of change and interpret the meaning of place without problem. In effect, therefore, the act of not trying to broaden and share understandings or not trying to reach out and hold onto the periphery is a direct act that perpetuates exclusion.

5.6. Situating my voice and evolving my lens

In the following chapters participant voices are united and mixed. This process establishes my interpretive method of analysis. I acknowledge that the re-presenting of participant fieldwork information is bound to my particular point of view and that objectivity is not possible. The act of arranging and mixing conversation is the point at which narrative licence

begins and, while my preference is that my own voice be backgrounded, this presentation can only be, as Mansvelt and Berg describe of post-structuralist writers, a 'writing-in' where 'contextuality, partiality, and positionality' are present and influential (2010, p. 339). The act of choosing what is being presented and what is not being presented, the groupings and arrangements of speech, and the resultant discourse are contrived and subject to the objectives of the research.

> Research and writing are iterative processes, and writing helps to shape the research as much as it reflects it…Writing is not devoid of the political, personal, and moral issues that are a feature of undertaking research, nor is writing devoid of our embodied emotions as we sense and feel the narratives we construct. (Mansvelt & Berg 2010, p. 342)

The very epistemology and ontology that require challenge cannot be removed from this process. The recognition of this research as an effort to tell the experiential stories of five individuals must also be aligned with a recognition of the research as 'a partial perspective spoken from somewhere and by someone' (Mansvelt & Berg 2010, p. 343). I listen to their stories, their words in the context of my here and now, with the influence of my history and through my own lived experience of the built environment: my located socio-cultural experience, my innate cognitive and sensorial experience, my schooled architectural lens, and my experience as focused researcher of this specific topic. I acknowledge therefore that the words of these five people are chosen because they resonate with my hearing.

I insert myself into this process as architecturally tuned to the language of the built environment. My architectural lens heavily influences the listening that I do. As a trained and practicing designer of the built environment I am tuned to a frequency especially sensitive to words and phrases that conjure

spatial and structural imagery and, like many people with autism, I default to visual thinking and build things in my mind. My tuning therefore tends to prioritise information in spatial and textural ways; I listen to capture specific information, habitually receiving it as my brief and then instantly I begin the process of rearrangement and juxtaposition. I question use, interrogate function and, within a short space of time, I begin the process of problem solving. In the participant-researcher activity space, therefore, my listening is at risk due to the constriction of my hearing and, while this phenomena is something that I am acutely aware of, it was not until I listened again and again to the words of participants that I realised just how difficult it is to become more acutely attuned. The voices of these five participants are unique and their experience of Asperger's unfamiliar. Listening required a concentrated stillness of mind, openness, and a willingness to move into areas of discussion and reason that strayed far from the topic I had set out to investigate.

I position myself also within the context of neurotypical knowledge, with lenses that have evolved without embodied understanding of how urban environments can be experienced differently, or of alternative physiological impacts that can sometimes cause discomfort to the point of inflicting pain. Macklin and Higgs (2010, p. 65) state that,

> All researchers look through multiple and evolving lenses, some of which are integral to their identity, thereby constituting an internal frame of reference; others are external and contextual, but both impact on the researcher's priorities and goals and shape the way the phenomenon under study is viewed and understood.

What I take from this statement and put forth as justification and stimulus for this research is the concept of lenses 'evolving.' It is not possible to adopt a

lens of Asperger's experience and alter an 'internal frame of reference' but it is possible to adjust the focus of 'external and contextual' lenses to broaden apertures and reshape understandings. This research is part of the evolution of my lens and a contribution toward the evolution of others. Macklin and Higgs (2010, p. 65) state that our 'Lenses, like values, cannot be removed'. I extend their statement and add; but they are not unreceptive to new perspectives nor constrained by boundaries, our lenses can evolve to become more comprehensively aware and more holistically perceptive.

Conversely, it is the intention of this study to encourage and not to question the fully lensed perspectives of participants; this is the essence of the research.

5.7. The score of experience

5.7.1. Visualising voices – similes of understanding

> Moving elements in a city, and in particular the people and their activities, are as important as the stationary physical parts. We are not simply observers of this spectacle, but are ourselves a part of it, on the stage with the other participants. Most often our perception of the city is not sustained, but rather partial, fragmentary, mixed with other concerns. Nearly every sense is in operation, and the image is the composite of them all.
> (Lynch 1960, p. 2)

Conceiving of urban spaces and urban places as two and three-dimensional entities is comfortable; conceiving anything beyond the tangible and observable third dimension is, as Einstein and other physicists have exposed, not easily conceptualised and mostly beyond the realm of human

understandings. In the context of the environmental experience being pursued through this research I propose that the symbiosis of spatial meaning and feeling—the connectedness sensation—is a fourth-dimensional experience, one that is subject to individual perception. Things that operate in this non-tangible, non-visual and time-dependent, fourth dimension-like space are difficult concepts to understand and describe. The following similes provide the conceptual explanations that background and advance these proposals.

I visualise participant voices. I consider their pregnant experiences as a thing, a tangible thing that visually manifests and fills the spaces between the structures of urban places. I imagine this thing of experience as having many faces and possessing many forms: a sculptural and dimensional entity sometimes rigid and structured, sometimes fluid and amorphous, sometimes opaque and sometimes transparent. It is a thing that occasionally appears as strength and at other times as weakness, it can be a thing of permanence, static and steadfast, or a thing of transition, evolving, transforming or mutating from one state of being into another.

Art theory would conceive this thing as the negative space in an artwork, the space that surrounds the positive objects and 'helps to define the boundaries of positive space and brings balance to a composition' (Creative bloq 2018). Artists understand that negative space is not negative however; the term inadequately describes the power of its presence and the symbiotic relationship between the two space-types. The complement of positive and negative space is in fact inextricable, with each part equally critical to the whole. 'Negative space is never blank. It is designed to support the foreground of the picture … Without negative space, the positive would have no meaning' (Roberts 2018). Like the sky of Van Gogh's *Starry Night* where meaning 'beyond the representation of the physical world' is conveyed

through an intensity of colour and brush stroke, through the ‘swirling, tumultuous depiction of the sky’, the space between the objects depicts and invokes feelings beyond the two dimensional canvas and the three dimensional subject (2012).

This thing of experience parallels a music score that determines the mood and feel of a movie scene; music fills the space—the gaps between objects and the spaces between people within the scene itself and within the place where the movie is being screened. A score is recognised as a narrative tool. It establishes meaning by triggering feelings that induce emotional responses to activity and place. Within musical composition the spaces between the notes, progressions, rhythm, and parts are as critical to the piece as the notes themselves; combined, this arrangement then determines the feel. As audience, our individual responses to activity and place immerse us in the scene in front of us and resolve our feelings. We are then related and connected, in one way or another, to the environment, on-screen and off-screen, and if the filmmaker and the score composer are in their minds successful, we will feel generally as they intended, but with a depth and intensity drawn from our own experience. Less success implies less resonance. What each of us takes from the film will be uniquely personal and I conjecture that films (like environments) that are widely successful have the ability to educe meaning from many different aspects on many different levels—they resonate with different people for a multitude of different reasons. Effective and powerful music scores often become autonomous, transcending the film for which they were created, operating as an independent and provocative voice, transferring feelings to different times and places while continuing to evoke their original intent.

Similarly, the spatial experience of people is impacted by the compositional structure of the fixed and animated components of place and affected by the

intangible and the invisible, by the emotive feeling of the place. In the context of urban design, the Score of Experience is the meaning that fills the gaps between buildings and the spaces between people—at once nebulous and definitive. Meanings will derive from bodily interaction with static componentry as well as with the position and activity of others occupying the same space. For the user of spaces meanings can feel individually ascribed or they can feel unified and collectively understood and both scenarios provide opportunity for personal connection or conversely, reason for disconnection. Derived meanings instantaneously determine distinct feelings, which for the most part are subliminal. Yet we know when we feel welcomed to a place and when we feel we do not belong, when we feel unease to the point of threat or comfort to the point of nourishment. We will consciously avoid a place without foregrounding the reasons why and we will frequent a place because it has *that thing* we seek at that particular moment in time. The meaning of place therefore carries the weight of our individual and bodily judgement of success.

For the everyday built environment instated meaning is typically subtle, and for the majority of people—those with aligned experience—the instated meaning will be unrecognisable and easily adopted because of its *fit*. Thus, the more in tune a visitor to a place is with the psyche of the designer, the more likely it is that the experience is harmonious. Those who find themselves to be at odds with the designer and not in tune are more likely to feel incongruous and uncomfortable, less welcome and more isolated. Their Score of Experience will be less likely to encourage them to return for an encore.

5.7.2. Synthesis and analysis

In Chapters 6 and 7—synthesis and analysis chapters—I have assembled a narrative of words, statements, responses, and conversations as reply to the foundational questions of this thesis. Generally, both chapters focus on the first two questions of experience in shared urban spaces, and the influence of experience on everyday geographies. Although these questions are neatly partitioned, participant stories are naturally more organic and deeply intertwined. The two chapters therefore are not arranged to specifically address each question, rather, they are organised by experiential themes and the narrative in each has a reflective serendipitous flow. The work in chapters 6 and 7 is a synthesis and analysis of participant *discussions*. The narrative is multi-vocal, interpretative, and reflexive, structured to evidence a range of perspectives on built environment experience. Narratives of the five participants are mixed with my own; participant experiences are organised by theme and I weave in narrative that binds, that situates stories within literary context and discourse, and that provides interpretation of meaning. In this work I employ Chase's (2018, p. 549) definition of narrative:

> a personal narrative is a distinct form of communication: It is meaning making through the shaping of experience; a way of understanding one's own or others' actions; of organising events, objects, feelings, or thoughts in relation to each other; of connecting and seeing the consequences of actions, events, feelings, or thoughts over time (in the past, present, and/or future).

In chapters 6 and 7, I provide participant's fieldwork *information* as interspersed quotation and summary through contextual narrative. I have not included *information* in raw form. The photographs, diary notes, GPS tracks,

email correspondences, and transcripts contribute to the narrative but are excluded to, (1) maintain participant anonymity, and (2) because participant *information* was intended to provide supporting detail and context for the *discussions* and to empower the participant as owner of that detail and context, it was not intended to be shared as qualitative data. This approach in general, facilitated my intentions to have participant *discussions* lead primarily by the participant. Also, by placing primary emphasis on the *discussion* as the source of narrative, the differential in participant *information* is equalised. Participants, who elected not to undertake any form of fieldwork and instead to only partake in discussion, are given equal representation in the narrative.

The theme of Chapter 6 is ableism. It is a critique of encounter with ableist culture, divided into the sections of difference, diversity and discipline. This chapter explores personal journeys of encounter with, and reaction to, environmental exposure within the contemporary perspective of normalcy.

Chapter 7 is themed with discussions of connectedness. It examines experiences under the subjects of confinement, constructions and connection by reviewing the everyday geographies of the participants and their feelings of, and means for, connection. In it I argue for the criticality of environmental connection, consider the varied ways in which it can be achieved, and reflect on both the practice of, and the value in blurring the social and built environments.

chapter 6

Through Asperger Lenses

A collaborative score of experience

Part 1- Ableism

The physical construction of urban space often (re)produces distinctive spatialities of demarcation and exclusion

Indeed, the socio-spatial patterns of ableist values are etched across the city in numerous ways, forming a type of architectural *apartheid*

Imrie

(2001)

6.1. Chapter layout

This chapter is a collaboration of voices where the declarations made by Andrew, Grace, Patricia, Rob, and Stuart are mixed with my own interpretations and structuring choices. My aim is to highlight the individual, parallel, and sometimes conflicting, scores of participant experience. Work in this chapter examines participant encounters with the built environment and with shared urban places where decades of approaches to equitable access have already been implemented. Participant stories reveal the meanings each person finds in the gaps between buildings and in the spaces between people, and aid a better understanding of how those experiences influence everyday geographies. Ultimately, this chapter is a means to explore whether, how, and to what extent, participant experiences can provide insight into how urban design practices can foster greater inclusion.

Participant discussions revealed personal encounters with ableist culture. That is, participants explained how personal adjustment and self-discipline were necessary for their entry and inclusion into both socio-cultural and built environments. Such adjustments and disciplines are physiologically and emotionally personal and subject to both spatial and temporal influences. In moments of alignment, when appropriate adjustments are made and self-disciplines are adopted, entry into social and built environments can occur. Then it is possible to operate without any significant adverse effects on other people and to maintain common standards of behavioural conduct, and in doing so, uphold the prevailing order of normalcy. This process however, perpetuates ableism by preserving the position of the able and reinforcing participants' feelings of difference.

On this basis, in what follows in Chapter 6, I have arranged discussions about ableism to convey both participants' stories and my interpretations of these as surfacing three key themes—difference, diversity, and discipline.

The chapter starts with the theme of *difference* under the title, *But I'm different.* It explores participants' ontological positions. At times, there is direct and verbalised comment about a person's relationship with others and with the built environment but sometimes that relationship is evident only observationally by reference to the nature of the interaction. Discussion in this section reveals that personal experiences of difference are perceived, lived, and accommodated by each participant in different ways, and that participants view the constructions that generate their experiences of difference to be fixed and intransigent.

And your universal approach doesn't help much, is the title given to the second theme, *diversity.* It challenges contemporary understandings of this term, describing what happens when environmental interactions move beyond built-in assumptions about difference. This section provides both direct and indirect commentary on contemporary universal design approaches; it underlines deficits and exposes absences. It also offers one view about how future universal approaches might improve their reach and resonate more widely.

The third theme of *discipline* entitled, *But I want to be social, so I'll discipline myself to fit in,* is a reminder that the want for inclusion is human. Work in this section challenges the idea that preference for self-isolation is symptomatic of Asperger's and it exposes some of the methods and efforts used by participants to be included into social and built environments. It evidences the societal imbalance and ableism perpetuated in common expectations; the belief that people deemed different will adapt to and change their behaviours

in public such that the 'normal,' 'neurotypical' majority remain unaffected and unchanged. This section provides the basis for my contention that there are *different spatialized ways to be social*, which is developed in chapter seven and discussed in chapter 8.

6.2. *But I'm different*

But I'm Different explores participants' ontological positions. In this section I have combined stories and comments from each person about how they view their lives, about how their Asperger identities are, or are not, recognised by others, and about how this recognition influences their experiences. Participant stories in this section reveal when and how each person feels *different* and discussion explores participant views on the construction of *difference* and it's ability to change.

'Well I'm a little bit different, aren't I?' asked Rob. 'Are you? Do you believe so?' I asked. 'Yeah, oh yeah,' he responded, 'there's a lot of different areas and they're all interrelated' (interview, February 2016).

Difference is a barrier word; once you have decided that you are different, or others have labelled you different, the factors determining differences can magnify to become insurmountable. Initially in 1993, Jim Sinclair (1993) suggested that the first step to understanding autism was to recognise difference as an alternate way of being. This act, he suggested, would allow the expansion of the definition of normal, and then by suffusion, aspects of the environment—those within human control—would ultimately change to accommodate a broader spectrum of people. Speaking with me in 2015, Rob identified with being on the autism spectrum, and recognised his differences as 'alternate' in ways neither noticed nor understood in society.

Thus, Rob's differences from a putative norm remain a barrier to his engagement in the public domain. He is trapped in the ableism paradigm. His differences are not in themselves visible—sensitivities to loud noises or crowded places cannot be seen on a person's body and only become visible when behaviours considered inappropriate then manifest. 'You might be sitting next to a thoroughfare and someone might bump you or something; that really short-circuits to my fight or flight response,' he said (interview Feb. 2016). Only then, and only possibly, would those around him bear witness to his sensitivities. Typically, Rob chooses not to subject himself to challenging environments. He either stays at home or limits time spent in public places so that he is only partially and peripherally engaged.

Rob, now in his twenties, reflects on his school years as a time of discomfort and social awkwardness during which he 'just generally didn't mix that much' (interview, February 2016). Now, without the routine of school to compel him to leave home, the adjustments are mostly too great. 'I got a lot of things that get on my nerves unfortunately, I try to do something about them, I try to manage them but they just seem to go straight to that kind of high response kind of thing in your brain' (interview Feb. 2016), and 'I'm trying to push myself to do a bit more [driving] again' (interview, February 2016). Rob's embodied barrier of difference however, is well established and his compounded anxieties keep him mostly at home.

Stuart's school experience was different from Rob's. His autism was diagnosed in year seven and the school he attended provided specialised support.

> That [room] was a very insulated kind of environment, we were kind of implicitly discouraged from going out and mixing with the wider school community … and on top of that I lived one hour away from the school so I didn't mix with the mainstream

> community inside the school or out of it. (Stuart, interview August 2016)

Thus, by the age of twelve or thirteen Stuart was diagnosed with autism and determined as not suited to a *normal* school environment. This labelling can be viewed as both divisive and supporting. Being diagnosed separated and located Stuart into a specialised and 'insulated kind of environment,' a room where he was shielded and not required to mix with the 'mainstream' school community. Physically and spatially, the room located him fully within the school but its sanctioned separation meant that he did not have to be completely entrenched in school social life and it provided him with a place of retreat. Although the likely intent of the autism support program was to moderate his differences, to make him more resilient in a *normal* world, Stuart was given opportunity, time, and a safe place to trial those moderations.

Stuart did not begrudge his organised separation from 'mainstream community.' On reflection he endorsed that space as an adjuvant place—a place of discerning access to normal; 'In grades eleven and twelve I was outside of that environment; it was a pretty radical change but I think I came out the other side of that much better off for it' (interview, August 2016). The separation had provided him with a protective and supporting cocoon and a vantage point from where he could hone the skills necessary to leave the more insulated environment of the school and to move more confidently into the mainstream.

Stuart defined difference in spatial terms. Being on the outside meant different, and being on the inside meant normal. His description of the change that occurred after moving from one position to another in order to 'come out the other side,' was of 'radical change' and it was the provision of the third space that augmented this process giving him a greater chance of a

successful transition. Having access to an insulated and supporting adjuvant place provided Stuart an intermediary position, a bubble of protection from, and for learning about the *inside* while remaining part of the *outside*. In the context of contemporary constructs of normalcy and difference, Stuart's early label of difference was supportive.

Andrew did not experience early support or intervention. His initial response to the question of Asperger's diagnosis in the fieldwork invitation was: "I don't know, the diagnoses have been conflicting. I got an, "on the balance" yes, a strident no, a "you show clear signs, but you could make a case for most post grad students" 10 minutes into an appointment, and a bunch of "I don't knows" (email, September 2015). 'My diagnosis is conflicting', he said, 'I am externally diagnosed by some as Autistic, by others as ADD/ADHD; and of course by others still as normal' (diary, January 2016). This diagnostic confusion unsettles Andrew such that he often refers to himself as 'weird' (diary Jan. 2016). Andrew's confusion and lack of clarity however are not surprising when reflecting on the changing status of autism diagnosis—discussed in chapter 1, section 1.1.2. The history of shifting definitional criteria for autism that now places autism as an umbrella term for autism, Asperger's, childhood disintegrative disorder and Pervasive Developmental Disorder, combined with the spectral breadth of experiences of autism, leaves space for uncertainty and misunderstanding.

Although confusing, formal diagnostic certainty does not alter how Andrew feels. 'I've long known that I needed some contact with "normal" people. "Normal" means not my family and I need as much as possible, to try and understand people' (diary, January 2016). Andrew's assessment of his family as *not normal* can only be viewed in the context of his frustration with his living situation. He spends most of his time with his parents; they require his presence, demand his assistance, and minimise his exposure to other people.

Andrew's anxieties are magnified by this frustration—with his incapacity to take charge of his actions, and his failure to reduce his parent's control.

> I describe myself as not having any control over my life which isn't true, it's like so many things, simpler but it isn't entirely true … It's trying to fit fifty years' worth of my life into one bedroom … it's more I guess an impatience but after, what is it, something like fifteen years now I guess the impatience is justified, I just don't have the ideas, the confidence to do whatever to be able to move out of the house and stop it, and if I did have all of a sudden it's like I moved out of the house but I still have to go back and forth all the time to take care of mum and dad, what's the point of moving out of the house is the rational view. (interview, January 2016)

Rational was a word Andrew often used to describe a viewpoint that he deemed preferable. For Andrew, *rational* was representative of *normal* and necessary to a healthy life. He stated that his autism isolated him from 'rational people' (diary, December 2015). He described the importance of making 'rational attempts to think' (diary, December 2015), the need for 'things that are rational' in his life (diary, December 2015), and the natural environment, as opposed to the built environment, to be a rational place (diary, December 2015)—a viewpoint discussed in more detail in Chapter 7, Section 7.2.3. Andrew did not however define what he believed a *normal* person to be, only that he felt he was not. Through a consistent barrage of negative responses to the way he acted and reacted, Andrew resolved that he was different to *normal*, that he did not behave in the same *rational* way that other people did, or more often, as other people told him he should. 'Some would say [my] experiences caused normal reactions, some wouldn't. Others have even been quite blunt in suggesting that I am not allowed to react

emotionally' (diary, December 2015), Andrew explained. His confusion about how he should react to people or act within interpersonal situations was confirmation of his differences.

Andrew's late-in-life diagnosis means that he reflects on his experiences through a veil of evaluation. He tries to assemble each experience into a category of either 'normal' or, 'because I am on the spectrum,' constantly re-evaluating and questioning his determinations. This lack of clarity about what his differences mean is as much—if not more—of a barrier to his world-space as any clearly defined understanding.

> It's one of the freaky things about this autism is I'm supposed to, or anybody with a disability is supposed to, have specific needs and I can't for the life of me figure out what they are and how to get them. (interview, January 2016)

It is possible that Andrew cannot resolve an autism diagnosis with his identity. After forty-three years of relationships, employment, rural and urban living, Andrew does not see himself as different to the others with whom he shared those experiences, but now he cannot find connection with any particular group, nor an understanding of why he now finds himself in a removed position. Descriptions of his experiences correlate with some of the definitional criteria for autism such as 'responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building appropriate friendships' (American Psychiatric Association 2013a, p. 1), but the incongruence with other characteristics undermines his certainty about his actions and reactions, and places him at odds with groups of people and organisations that have certainty and defined purpose. It is a position Andrew portrays as; 'it's a classic of - is my concern normal, or exaggerated due to autism?' (diary, January 2016).

The absence of a definitive diagnosis is now Andrew's defining identity. He is acutely aware of his experiential differences but unable to reconcile them with the characteristics of either autism or Asperger's. 'I think for me there's just never going to be any more certainty in my life' (interview, January 2016), he said. This in-limbo position extracts from him what society expects that he position himself either into the norm and act accordingly, or outside of the norm and act symptomatically, that is, be different, look different and provide to others, assurances about their own status of normal.

Andrew's struggle to reconcile forty-three years of life without feeling different, with his current state of uncertainty, confronts the socio-cultural positioning of diagnosis. Did Andrew's differences actually intensify, or did the changing landscape of diagnosis effect the socio-cultural positioning of autism such that perceptions of his differences altered, or was there a shift in the acceptance of Andrew's perceived differences because of his aging? The perceptions of difference are clinically defined but also personally bestowed and externally applied, with each position having effect on the other. In a critique of the revision to instate Asperger's under the autism definition, Grinker (2010, p. 23) discusses the 'misleading and invalid' potential of clinical diagnostic characteristics, stating that their 'boundary lines are drawn as much by culture as by nature'. The non-clinical framing of autism has the potential to invert the positioning of difference.

> If you ask my daughter, Isabel, what Autism means to her she won't say that it is a condition marked by impaired social communication and repetitive behaviors. She will say that her autism makes her a good artist, helps her to relate to animals and gives her perfect pitch. (Grinker 2010, p. 23)

Grace too describes herself as a good artist.

> [Local disability services] does programs for all different levels of disability (from mild to severe) all in one group on particular days, I always feel a little bit left out that I'm one of the few good artists in this program. But it keeps me out of the house, and I'm always given my own art space there (diary, April 2016)

Grace's early and definitive diagnosis propelled dedicated focus on maximising her social inclusion and on celebrating and honing her strengths. Her self-described motivation is to satisfy the demands of her 'restless' brain (interview, April 2016) and to use her skills as broadly and as often as possible.

> I can use my art and craft ideas to make something completely different. It's like for instance I made something, I make lots of cards for people since I was a kid, and I have made a few handmade Christmas decorations and things for families, and I've been recently sketching Roman statues for families overseas, so people are starting to widen me up to the world of art a bit … and I'm going to be trying out landscaping. I'll be trying abstract art at the art club … well I am an artist and I have good taste … for instance I sometimes dress the models and think a necklace for this, a dress for that season … being an artist is busy, I'm just a volunteer and an art student. (Grace, interview, April 2016)

Grace's diagnosis of Pervasive Developmental Disorder was made in her primary years. Hypersensitivity to sound, crowded spaces and the gaze of people were directly described as problems for Grace during our

conversations, but Grace's vulnerability and gullibility due to her openness, literal interpretations and honesty were implied only contextually—by the continued presence of her mother for example. Grace's childhood included tailored assistance both in school and outside of it. Assistance focused on conditioning and minimising her intolerances. Grace and her mother described how specialised tuition had helped her and, like Stuart, they lauded the benefits of early intervention. In her adult years, Grace's autism symptoms were explained as tolerable—either by means of conditioning, or by use of aids such as earplugs.

A statement by Grace's mother evidences the weight of the socio-cultural positioning of difference and of diagnosis; 'I think we were very lucky with [Grace] because she was only mildly affected by autism, and also, a lot of the things that were problems for her when she was little are no longer problems', she said (interview, April 2016). Grace's mother's view of her daughter's autism as something she was 'affected by', something that could be and needed to be altered to meet socio-cultural expectations, and the suggestion that it is now mostly gone, exemplify the pervasiveness of the ontologies of *normal* and *difference* and the unmoveable positions that they occupy. Grace's *differences* are now conditioned to a point where she can better tolerate public encounters and integrate more *normally* into public places.

Like Stuart, Grace's years of ASD-specific training taught her how to cope in a world that does not accommodate her differences but it is impossible to understand the new location of her intolerances. Did her hypersensitivities actually physiologically diminish or are they supressed and contained so they do not expose themselves in public places? Our conversation suggested that for some—like noise and the direct gaze of other people—it is a matter of suppression. Others are possibly diminished or changed so they are no longer problematic.

Being different and having different built environment experiences are for Patricia two separate and distinctly contra positions. The former is personal, diagnostically explained, and tightly held, and the latter, shared, universally problematic, requiring examination. As described in chapter 5, section 5.4.2, Patricia's diagnosis like Andrew's, occurred in adulthood. It was a self-diagnosis that resulted from self-directed research and deduction, an outcome Patricia described as relief. In her published writings Patricia explained a feeling of being peripheral as her motivation for seeking answers. Once self-diagnosed, she was able to make sense of her differences and that definitive position provided her freedom to remain on the periphery without self-reproach for being there. If Patricia held any feelings about either different interactions with other people or different experiences in urban spaces, they did not enter into our conversations. Her engagement with the built environment was pragmatic and the way she conducted her fieldwork revealed a removed and observational approach to life.

> Levees are good for walking along. The garden on the corner looks like a good idea that didn't go anywhere. Also, I always think [the sign] says, "Adopt a Pastiche" from a distance … it's not a good idea, it's 'adopt a garden,' what does it say, 'adopt a patch site' … yeah, well they're not really doing it! That corner is bad for crossing. Vision is obscured by the fancy fence thing, and cars come around there quite fast, they don't want to wait. The new levees seem to want to separate people and bikes, but everyone walks, seems to walk their dog along the bike one … the bike one is along the actual river and the people one actually goes up and down so you can get good views but people like to walk along the river I think, when they made it they had a good

> idea to separate the traffic but it's not working. (Patricia, diary and interview, August 2016)

Critical to our conversation were photographs and the diary notes and GPS maps resulting from Patricia's fieldwork. They provided dedicated discussion focus and meant that facial gaze could be minimised. Patricia educated me about her experiences but she also spoke for others who use the same streets, footpaths and bus systems. Problematic encounters or observations about ill-conceived urban constructions were expressed impersonally and as universally applicable. Her commentary on footpaths, for example, which recurred throughout our conversation, was an expression of concern for all users.

> Yeah, well they don't think about it, they think they're making allowances for pedestrians I think, but they don't … well often they're not there or they're difficult to use … There's a footpath along the West Tamar Road that I assume is intended for people to walk along. Originally.
>
> The one [in the photo] with the telephone poles down the middle of it, I asked.
>
> Yeah, cause it's a footpath! I think that when they widened the road they didn't bother widening the footpath … it's a crap footpath, especially if you have a pram or something. (interview, August 2016)

Patricia's perspective on her urban experiences presents a paradox. The embodied feelings of difference that drove her to seek explanations, and her subsequent self-diagnosis, suggested that she would recognise and

acknowledge there might also be differences of experience in built environment interactions. However, Patricia did not describe nor evidently perceive her interactions with the built environment as atypical. Although she recognised herself in the descriptions of Asperger experience, she did not consider the way she engaged with the built environment to be different to that of others. Patricia's reflections and evaluations did not include notions of unique interaction. She deemed her built environment challenges to be just as problematic for non-Asperger others. She viewed flaws in the built environment as flaws in common, and componentry that positively assisted her urban habitation as important for everyone.

> Seats, I like these ones, a lot of them they put a rubbish bin next to them and you've got to sit next to the rubbish bin, and these ones are good and others look like they're put there for a particular purpose like taxi stops or outside shops or something but these one are a good spot to just stop, if you just want to stop, to stop if you need to sort out what you're carrying or something

> ... these [seats] are not so bad, the red and yellow ones, if there weren't rubbish bins next to the seats. There's pretty good placement here though, most of them are in the shade and there's some facing the library doors for when you're waiting for the library to open and some facing away from the doors for when you don't want to go to the library, yeah that's a pretty good are actually. (interview, August 2016)

One tenet of this thesis is that the reduction of built environment discordance for people with autism will be beneficial to all and Patricia's stance of being non-unique is central to that argument. Another, more ironic suggestion is

that it is Patricia's Asperger's view of the experiences of others that sanctions her non-unique perspective. Baron-Cohen's 'mindblindness' theory—Theory of Mind—proposes that people on the autism spectrum experience degrees of deficiency in their ability to 'infer the mental states of others (e.g. their knowledge, intentions, beliefs, desires)' (Ozonoff & Miller 1995, p. 417), that they are 'blind to the existence of other minds' (Baron-Cohen 1995, p. xvii). It is therefore possible that Patricia may not perceive or believe there to be a different type of experience to her own. While she described feeling that the wiring of her brain is different, and that forming relationships with other people is difficult, Patricia did not suggest that her interactions with the built environment are different to that of other people. For her, the built environment has practical purpose to facilitate and provision for the everyday activities of its users, whomever they are. Without appreciation that other people might experience different physiological or emotive responses to built form, it is reasonable to expect that everyone will consider the positioning of a public bench and the provision of a continuous and unimpeded footpath impractical.

For Andrew, Grace, Patricia, Rob and Stuart, their experience and ontological positioning of difference is varied. Personal differences are confirmed by diagnosis, by the direct and implied advice of others, through years of challenging environmental interactions, or by a combination of all factors. They are five people who have unique experiences of difference, are unique in the ways in which they perceive and manage their own understandings of difference and the perceptions of others, and unique in the ways in which they engage with the built and social environment because of it. Patricia does not deem her personal idiosyncrasies, those characteristic of Asperger's, to have significance in a built-environment/ableism relationship that requires any specialised response. She maintains a peripheral position with no comment on difference. For Stuart and Grace, being diagnosed at a young age armed

them with strategies to align their differences with the putative norm, which enables them to satisfactorily navigate and to occupy social and built environment structures. These strategies now make their adult built environment interactions bolder. Conversely, without early and tailored interventions, Rob and Andrew describe more restricted and less socially integrative connections to public urban life.

6.3. Diversity

And your universal approach doesn't help much

Differences are diverse. Varied capacities and methods for access to and engagement with the built environment should mean there is built-in accommodation for those variances. A built environment that compels the disengagement of some people, while others are relieved from having to, is, however, what universal and inclusive approaches to design are intended to address. As discussed in chapters 1 and 2, shortfalls and limitations of universal design, inclusive design, and their associated standards and guides, do not restrain ableist geographies (Imrie 1996, 2001; Imrie & Thomas 2008) and for people on the autism spectrum who have been mostly excluded from consideration, they have had little beneficial effect. People remain isolated, environments remain inaccessible and the majority population remain oblivious to both situations. The typical problem-solving approach and design-solution response employed in universal design applications is subject to a 'symbolic and cultural encoding of the city' (Imrie 2001, p. 233) and that encoding anticipates a typical neurology. The manifestation of universal design is further encumbered by the production and evolution of reductive componentry. Once this componentry establishes itself in the world of institutionalised marketization and commercial viability, it is

difficult to shift (Imrie 2012; Whyte 1980; Williamson 2012). Patricia made specific reference to some of this componentry.

> The lift buttons ... They use symbols, which is good and all that, but it takes more processing time to "translate" them, so if someone is, in this case, approaching the door and you want to hold it open for them, by the time you've worked out which button to press, they've closed ... where if they just said, 'open door', 'close door', you'd know straight away, it's like they put all these symbols on it and it isn't really helpful.
> (Patricia, interview, August 2016)

The typical, universally accepted lift button 'door open-door close' symbols have failed the processing method unique to Patricia. I am unable to assess whether difficulty with this particular symbol is a common occurrence for people on the autism spectrum because I do not have comparable information from the other four participants, nor autism research data specific to that symbol. Patricia's need to 'translate' the symbols however is evidence of one breakdown in understanding. It may be that she finds that the symbols in isolation are hard to translate or it may be that their inclusion into a panel of other symbols, numbers, buttons, directions, sounds and lights, combined with other sensorial pressures associated with the lift—such as the close proximity of others—is problematic. What is also surprising, and a valuable reminder of the dangers of stereotyping, is that these symbols, as imagery rather than words, were found to be less instructive for Patricia. Visual or associative processing preference is suggested to be a typical characteristic or strength of autism (Grandin 2006b; Grandin 2009a; Samson *et al.* 2012) and accordingly, visual communication methods are commonly used in autism learning programs and as communication tools (Preis 2006).

It is possible that this particular symbol has never been subject to an officially documented evaluation by people on the autism spectrum. There is also a possibility that this symbol has never been formally access-evaluated, tested or re-evaluated and its perpetuity exists because of assumption and marketization (a question for alternative future research). The pictorial images themselves were most likely developed to replace words for the purposes of overcoming language differences, thus facilitating international marketization. The 'open door-close door' symbol therefore is not necessarily aimed at a particular cohort of the population; it is general advice assumed universal and provided as a directive to all users.

With the intent of universal design being to ensure that the 'designed environment is amenable to ease of use by the greatest number of people' (Imrie 2012, p. 874), the lift button symbol cannot be deemed wholly unsuccessful—a great number of people successfully interpret and use the buttons on a regular basis. Lift operation symbols however are not consistent in their imagery. They vary with product manufacture, are stylised and amended, increasing the possibility that confusion might also be perpetrated by inconsistency. It is the continued assessment, broadening and improvement of built environment universal design applications that Patricia's observation represents:

> you see that round a lot, they put these symbols up thinking because they're universal symbols everyone knows what they mean but it's not always that automatic.
> (Patricia, diary, August 2016)

Patricia noted another practice of assumed understandings as confusing,

> They do the same thing with the recycling bins, they've got the red and yellow recycling bins and they don't actually say which is the waste one and the recycling one, sometimes they do, sometimes they say waste and sometimes recycling, but sometimes they're just colour coded and I think which one am I supposed to use? (Patricia, interview, August 2016)

Again, Patricia's observation and reaction to bin types is not necessarily something that could be wholly attributable to an Asperger's idiosyncrasy. The practice of colour-coding bin lids in lieu of using words is likely confusing for many people. It is also not a universally directed standard but a practice adopted and adapted by local authorities, making the delivery variable. What is significant however is consideration of the contribution that the consistency and uniformity of this small piece of environmental infrastructure could make to a more legible environment. If universal design is to be truly universal and penetrate into all aspects of people's lives, then it is necessary that even the smallest pieces of social and environmental infrastructure are challenged and improved. Such efforts, made at a foundational level, will have broader impact, challenge assumptions and more effectively contribute to awareness, and in doing so help to facilitate and perpetuate understandings. The outcome of this change would not only benefit Patricia, but also educate and heighten the awareness of everyone involved in the process. Ellard (2015, pp. 221-223) states,

> Armed with understanding … any intelligent, well-informed citizen should stand ready to enter the fray, offer an opinion, and contribute his or her own vision to the debate about how our built environment should unfold … We must work in partnership with those who do have such expertise, and the best way to achieve such a partnership is to find a common language. The

> best ally for policymakers, planners, designers, and architects will be a well-informed public that not only understands how to listen to their senses and interpret what they hear in light of what is known about how buildings affect us, but also stands ready to contribute to that knowledge by carefully monitoring their own feelings as they explore the built world.

Ellard's idea of gaining opinion and insight from multiple visions and working toward a 'common language' is an ideal scenario, but I query how to gain input from silenced or reluctant voices that are either disenfranchised or engaged in trying to *normalise* their behaviours? Is a common language actually what is required? Might this also run the risk of a new common language with a new normal—a broader version of what we already have? Given the diversity of difference, should the objective be more focused on providing multiple options that provision multiple ways for people to engage?

One of Rob's comments about his ability to occupy urban places gives focus to this provision; 'I get kind of irritated when I can't move freely, when I bump into things, but generally I only need about a square metre to feel comfortable, I don't think it's asking too much' (interview Feb. 2016). Rob's request is reasonable and his challenge to urban shapers is not simply about access, but about access to spaces within spaces. Compartmentalised, semi-transparent, semi-immersed spaces that provision differing degrees of protection and differing levels of inclusion could offer Rob more comfortable access. Being in a space that gives further choice of spatial density or further choice of social immersion would provide Rob with greater opportunity to be present. With such options, Andrew too could increase his time spent in the company of non-family others. He may be able to avoid having to escape

from the very places he attends for the purposes of combatting his feelings of isolation:

> it's like you can see here in this club house now with just the two of us, 90 people get in here and start yammering away, you want to walk out … I sort of think you just have to close the walls and ignore everyone cause you're in such close proximity to each other. (Andrew, interview, January 2017)

The existence of diverse spaces within spaces, as suggested above, could supply the 'walls' Andrew describes, walls of varied densities with differing exposures that provide him extended opportunity to be social. For Rob and Andrew, knowing they could enter a space and within it find an adjuvant space with a comfort level that allows them to stay—one that was more liminal, more observational, less occupied and less chaotic—would enable greater physical access and importantly, furnish a personally attuned level of socialisation. Rob's desirable square metre of space, like Andrew's personal zone of comfort, are dependent upon the characteristics of the place—the noise level, the smells, the type and intensity of activity being undertaken by its occupants—but the key to their ability to remain and to occupy a space for a chosen length of time is having appropriate options.

Spaces of singular character and exposure such as a large, open-space, brightly lit, crowded, and unpredictable supermarket or shopping mall, offer few options for managing immersion. Waiting in the car for 'about 90 minutes' while his parents complete the weekly grocery shopping is how Andrew addresses his anxieties about the supermarket (diary, December 2016). Rob's evaluation of the city mall at night was, 'it's not so bad cause there's less people around,' but during the day increased numbers of people and the lack in-between spaces absent feelings of safety (diary, February

2016). Neither the mall nor the supermarkets offer adjuvant places that can provision both feelings of safety and feelings of inclusion.

Places of public access, designed to accommodate typical and popular functions in urban environments tend to have a typical socio-cultural space-type identity. Shaped by the prevailing and dominant culture of the, 'Larger, wealthier, and more politically powerful groups' (Tauke, Smith & Davis 2015), places reflect majority ontology. Dovey (2016, p. 106) states, 'Place is a form of identity, at once social and spatial, a combination of spatial structures, practices and forms, and social narratives intertwined with morphologies and types'. Popular culture venues such as cafés, restaurants and bars for example—configured with crowded tables, chairs, and people—are a contemporary standard for, and a symbol of, social participation and connectedness, and there are few, if any, restrictions or guidelines that regulate varied provisions of comfort in such places.

> unfortunately looks are valued above other things aren't they... it seems to me these days they don't bother with sound absorption or anything like that when they design a restaurant, and it seems to be getting worse and worse, there's one out at the uni here that's just concrete, all just concrete ... there can be just like only three people in the whole place and their conversations just kinda echo and it gets too much for me and I can't handle it (Rob, interview, February 2016)

> oh yeah, these highly reflective surfaces ... yeah definitely noise pollution, this might be more of a policy than design sort of thing but I've found that in some restaurants or other places the acoustics are skewed towards one particular direction or something, so you know ordinarily there's chatter in places like

> that and usually it blends together into a bit of a drone, some places though in particular, they sort of reflect all of that noise and direct it into one particular place or another
> (Stuart, interview, August 2016)

Rob also commented on one component of urban places that has been consistently and extensively, considered and addressed in the precepts of Universal Design: 'I find I get quite anxious going to the toilet when there's other people around, yeah I don't like anything about it … I do kind of avoid public toilets at all costs' (interview, February 2016). Building codes, disabled access provisions, and standards regulate the quantity, sizes, and provisions for public facilities and those controls include rigid design specification for people with atypical physical abilities. Current provisions are a result of decades of disabled access awareness campaigning and part of the Universal Design catalogue itself, but they are still places of urban discomfort for Rob and his anticipation of the potential for anxiety controls his activity. 'One place that I refuse to go into now … that's those portaloos that they put up at events and things like that, cause I've had a bad experience' Rob continued (without disclosing his bad experience), and although a portaloo is not a standard urban environment provision, it is a typical facility for festivals and events which constitute a significant part of popular social culture. Attendance at those events therefore is not possible for Rob.

Stuart too noted a particular aversion to using public urinals. The lack of privacy and proximity to others was too confronting. 'I have not used one of those stand-up urinals or anything for ages and ages and ages, I have just avoided them completely … I don't really understand the point of them I guess' (interview, August 2016). While urinals are not the only provision in male public toilets, in an Australian context by regulation, they can be provided in greater numbers than traditional toilet cubicles. For Rob and

Stuart, consideration of being in public places therefore required consideration of the types of public toilet facilities that were available and this factor alone could determine the length of their outings or whether they attended at all.

With her sensitivities now mediated, Grace is able to navigate familiar public places without specialised assistance. Her acceptance of her discomforts and of the way she is compelled to engage with the built environment also means that she does not expect greater assistance than she already receives. Since leaving school, increased access to her favoured activities and programs is provided by the Australian National Disability Insurance Scheme (NDIS). This provision adds a dimension to Grace's life that Grace and her mother are both thankful for; 'For the first time, people actually asked what [Grace] needed.'

The alignment of formalised support with Grace's needs and personality has positively affected her access to the built environment. Provisions and guidelines of universal design for the built environment focus on product and componentry—which is discussed in chapter 2—but the relationship and congruence between the delivery of tangible outcomes and the delivery of intangible provisions also has a place in the evaluation of equity. In 1990, the precursor to universal design, the ADA (*Americans With Disabilities Act 1990* (USA)), included services and programs as part of its scope and, contemporary universal design philosophy continues to promote holistic social, cultural and experiential parameters. Assessment of the adequacy of appropriate and effective services and programs fostered by that philosophy is individual. For Grace, tailored support programs and activities have increased her (and her mother's) confidence enough to broaden her personal geographies such that Grace now enjoys a state of independence she would not otherwise have had. During a discussion about her increased

independence, Grace described a group interstate fieldtrip in which she had recently participated. She concluded her excited recounting with a telling comment to her mother; 'I didn't miss you,' she said (introductory meeting, March 2016).

Boys (2014, pp. 2-3), suggests that urban shapers need to consult experiences of difference to expose and challenge assumptions about 'disabled' people and to harness their creativity. Stuart could be considered a Boys' exemplar—a creative thinker with unique experiences and ideas to share.

> I've kind of wondered if there might be kind of ways to shape the environment so that it generates updrafts in the air currents so it's like redirecting air pollution of all sorts above people rather than just hovering around … over in Melbourne there were a few bits of infrastructure to do with the train network … I thought that since they need to circulate air, maybe they could expel that through the ground. (interview, August 2016)

My discussion with Stuart took place in August 2016, three years after Google had introduced their technologically smart glasses, Google Glass. He explained the technology, its pros and cons, and described why Google had retracted the glasses. Stuart suggested this particular technology could be useful for people with autism.

> I can imagine that in the not too distant future we may have things like that, that will just be able to pop up and display directions somewhere or you know you might be able to look at someone and it would use facial recognition software to look them up on social media software or something like that. (interview, August 2016)

In August 2018 Stanford Medicine published an article titled, *Google Glass helps kids with autism read facial expressions* (Digitale 2018). The application is not entirely consistent with Stuart's suggestion, and technology should not be promoted as the universal design missing link, but the combination of Stuart's skills and unique insight is inspirational. Challenging contemporary approaches to design with innovative ideas and ideals is something that nourishes design professionals and instigates progressive design solutions. Robinson (in\ Robinson & Pallasmaa 2015, p. 4) states,

> the cognitive and neurosciences, and the embodiment theory on which they are based, are revolutionizing knowledge across disciplines … To ignore the potential impact that neuroscientific research has upon architectural education and practice is to miss an extraordinary opportunity, since we are the very group that this new knowledge could most persuasively serve.

Differences are diverse and so far universal approaches to accommodate the diversity of difference in the built environment have not fully realised the breadth of their starting points—their foundational information remains narrow or abridged. This paradigm leaves people with autism—who have been largely omitted from built environment considerations—with irregular or limited access to shared urban spaces. Even with improved emphasis on diversity, and increased recognition and endorsement of the philosophy that environments are disabling, universal design approaches still operate within an ableist paradigm, and difference is still largely perceived as the property of the individual, not of the environments occupied. This position often extends to those who wear the label of difference who, through a lifetime of

socio-cultural construct, accept adjustment of difference as their responsibility.

The diverse experiences of autism and the diverse experiences of public spaces shared by Patricia, Rob, Andrew, Stuart, and Grace give some insight into the breadth of understandings that the built environment should be built from. What their experiences suggest is that diversity of experience will be better accommodated by a diversity of spaces—spaces within spaces, adjuvant spaces that can accommodate different levels of immersion into both the physical and social environments of shared urban space.

6.4. Discipline

But I want to be social so I'll discipline myself to fit in

Stuart described being social in place as a practice in self-discipline. It was something that could be learned through targeted and specialised rehearsal.

> Yeah, you know when I was a teenager for instance, thirteen to fifteen or so, um I was very, very anxious about being alone in crowded places and even needing to speak to shop keepers or anyone like that cause it was, it was just an overwhelming social anxiety … I guess that only started to change once I sort of developed scripts to follow cause they're structured interactions, you don't really need to think creatively. (Stuart, interview, August 2016)

The 'scripts' Stuart referred to are an assistive device that was developed by Carol Gray in the early 1990s (Gray 1998; 2019; Gray & Garand 1993). The methodology contrives scripts, termed 'social stories' to assist people on the

autism spectrum with social interaction. Social story methodology is now commonly promoted and widely used by autism support services. Social stories, Gray explains, are a 'social learning tool that supports the safe and meaningful exchange of information' (Gray 2019). Stories are developed between a support worker or carer, and an individual. They are specific to the person, to their particular needs and understandings.

Critical to Gray's social story methodology is a foundational philosophy that helps shift the balance of misunderstanding to a shared and unbiased starting point. The philosophy has three principles. It requires belief that: (1) the social impairment in autism is shared, with mistakes made on both sides of the social equation, (2) each person's perception of a situation or event is regarded as valid and deserving of respect, and (3) it is necessary to abandon all assumptions and firstly seek to understand (Gray 2019). As Stuart stated, once he was in possession of a social story, he could develop a script and more easily interact with a stranger without having to 'think creatively.' It meant that the demand on his 'social readiness' (a condition described in detail in the next chapter) and anxiety about understanding what a situation or exchange might entail was temporarily eliminated, or at a minimum, relieved. With this methodology at his disposal, Stuart's options for social access increased.

Gray's (1998) social story methodology is comparable to Lorimer's (2003) 'small story narrative' approach to geographical critical analysis. Lorimer's approach recommends incorporation of personalised account as part of the process of capturing specific geographic episodes. It is 'upheld as a way of connecting, or re-connecting, conceptual polarities … in what was understood as a broadly scientific domain' (Daniels & Lorimer 2012, p. 3). The approach, Lorimer suggests, can yield enlivened stories that exist both in-and-of themselves, and, within a wider historical and methodological

context (2003, p. 199). Lorimer recommends there is power in the narrative type because it provides a contextual, 'sensitized' and 'spatialized' narrative of 'livedness' (p. 202).

Importantly, small story narrative 'provides scope to address and question official or established stories of place' (Daniels & Lorimer 2012, p. 5); personalised encounter and experience are given voice. Likewise, the social story methodology provides a means of gaining both physical and social access to place by removing the dominant voice of experience and replacing it with a personal one. These narrative processes therefore, not only make an individual's personal encounters central to the narrative, they also draw culturally defined qualities and essence of place into question. Generally accepted perceptions of place and the rules of engagement within them are brought into focus and challenged.

The social story method is a practice that can become routine and build confidence. As Bissell (2011, p. 2654) states, 'habit can enhance the efficacy of action'. Stuart's scripted narratives help to locate him into a specific place and allow him in that moment, to control the experience. The intentional act of creating a routine through structuring interactions provides Stuart with neurological space. It is a position from 'where the susceptibility to be transformed by the shock of the outside becomes less available' (Bissell 2011, p. 2662); it provides 'stillness to the pause for thought in order to proceed' (p. 2663). For Stuart, the practice afforded him independence at a significant time in his life, in his teen years when the act of building social resilience coincided with his progression toward adulthood.

Social story scripts provide a foundation from where less typical, more unpredictable, and spontaneous interactions can take place. From that position attention can be more easily directed and new resiliencies can be formulated. The practice however is neither accessible to all people nor

applicable in all situations. The application and extrapolation of social story proficiencies is subject to a person's initial ability—considering environmental sensitivities—to locate into the situation. Also, due to the spontaneity of most public interactions, it is not possible to prepare a story for all situations. And, like any method devised in a controlled environment, when it is undertaken outside of that controlled space, additional uncontrolled factors will influence the results. Stuart described how he managed such unpredicted and uncontrolled interactions. His tactics are discussed in section 7.3, *Construction*.

Social stories are engineered for social interactions, thus requiring animate—mostly human—counterparts. The non-human built environment, or the humanly saturated componentry of built environments is not easily addressed by the method. A small space, a wide-open space, a space that reverberates sound, or a place that houses a specific socio-cultural activity can require alternate or additional approaches to inclusion and for the individual, tailored self-disciplines. Tactics engineered by participants to improve their access and their engagements in public places are described in section 7.3, *Construction*.

Grace was also provided with early intervention-style training for the purposes of gaining access to places that were noisy and crowded. Grace's mother described how childhood conditioning helped increase her tolerance to public environments.

> A lot of things that were problems for her when she was little are no longer problems, so there was a time when walking through a big empty space or being here [in this noisy café] would have been totally confronting because of her ears, she didn't like assembly halls … Grace used to say that when she was in

> assembly she didn't like it because she could feel all the eyes boring into her and she found it very uncomfortable … they had to switch off all the hand dryers in the toilets because she couldn't bear the sound, she has, through us constantly engaging her in those things, in a non-threatening way as possible, they would say just come and sit in assembly for five minutes, and they'd increase it and increase it, so a lot of those things that a lot of people with autism have, have now gone for [Grace] whereas people with more severe autism still have that awful overwhelming sense of everyone's looking at me (Grace's mother, interview, April 2016)

The process of increasing tolerance to sensory stimuli to desensitise noise for example, is a direct process specifically designed to enable occupation—for both the benefit of the person with noise intolerance, and for the people who have to bear witness to or manage routines of intolerance. Hansen and Philo (2007, p. 500) discuss the adjustments made by disabled people to fit into ableist spaces and assert that people are ''provisionally allowed' so long as they seek to inhabit, utilise and conduct themselves in these spaces as would a non-disabled person'. Eventually Grace's conditioning assisted her to conduct herself in the same way as her peers and to enter the school hall more easily and to remain for assemblies. This discipline however did have personal threshold limitations and Grace described how she still employed her own method for maintaining tolerance, a construction further detailed in section 7.3—she hid behind her 'huge thick fringe.' Grace noted that it was not until she was sixteen that she reached an increased level of comfort and confidence and cut her fringe (interview, April 2016). The age of sixteen was also her final year of high school, after which she was no longer compelled to sit in school assemblies. From that point on, Grace had more freedom to choose which environments to inhabit.

The combination of conditioning trainings with tailored daily routines assists Grace in the progressive expansion of her personal geographies. The urban environment does not frighten her, nor fully deny her access, but she still requires a means for tempering sound and relies upon the predictability of built form and of other people's behaviour for her comfort. Grace carries earplugs that enable her entry into some places and extend her exposure in those less favourable, and she rarely, independently, ventures beyond places that are familiar. Grace and her mother attribute the broadening of Grace's public space access to her childhood conditioning and our meetings in the noisy, echoing café were testament to that success. As a child, noise for example, had significantly affected Grace's levels of inclusion—large empty spaces, the school assembly hall, toilets with hand dryers, and unpredictable public places with unpredictable noisy people were out of bounds.

Now, Grace can tolerate these spaces—like the café we had met in—but her tolerance is conditional. It is temporally bound and place dependent. There is still possibility for sensory attack. A familiar place, a measure of time, they were the factors of her tolerance and when the ear plugs lost their effectiveness and the gaze of strangers (real or perceived) became overwhelming, Grace's anxieties would return, and her differences would again be evident. 'You've sort of got used to wide open, large spaces,' her mother said. 'So, are the noises still there? I asked Grace. 'They still will be,' she replied. 'So, you've learned how to put them aside?' 'Mmm,' Grace responded, 'I'm sensitive to some noises unfortunately … so I guess you could say I still do have a tiny bit of autistic in me, extensions, a little bit, occasionally' (interview, April 2016).

Thus, Grace's sensitivities are not removed, they are supressed and disciplined into submission so that she can operate in hostile public places

without disturbing the world-space of others. With her earplugs barely detectable and her conditioning training unidentifiable, Grace is able to occupy and navigate public places without drawing attention to herself; her ‘‘appropriate’ and ‘normal’ appearance and behaviour’ do not challenge the ‘perceptions of normality’ held by others (Ryan 2005, p. 293).

> Grace, diary notes, April 2016:
>
> > Thursday 15/04/16 Day 8:
> > Before going to work … I managed to take a little bit of time to look around the new City Mission shop, after it closed for a few weeks for huge renovation.
> > Friday 16/04/2016 Day 9:
> > Went to the TMAG museum to see some new art exhibitions, while they’re still there.
> > Saturday 17/04/2016 Day 10:
> > Had a quick look at some of the shops at Channel Court in Kingston, before finishing off the morning by visiting the library and then heading back home.

This practice of self-modification facilitated both Grace’s increasing independence and the corresponding conventional societal expectations of her independence as she transitioned to adulthood. Behaving *properly* in public places, according to the prevailing socio-cultural and socio-political norms facilitates her access. As Ryan (2005, p. 291) states, ‘It is the “unconventional behaviour” of people that can “threaten disorder”’.

Grace did not bear any grudge against the actions of other people, the environment, or her place in it. Comments about excessive noise for example, were statements of fact with no blame attached; ‘I can forgive them’, she said of loud people on the bus (interview, April 2016), and when discussing

favourite city places she noted either avoiding noisy behaviour or adjusting to cope with it; ‘ there are some alleyways I quite like, you know well, where there are some unruly youths might wander around there and somewhere, and where there’s too much noise and too much crowd, unless I’ve got ear plugs’ (interview April 2016). While listening to her words and those of her mother, and observing the relationship between them, I perceived a position of acceptance. Grace said she is ‘quite happy most of the time’ (interview, April 2016). They presented a unified pragmatic perspective about Grace’s sensory challenges, firmly placing the responsibility for environmental tolerance, public participation, and access with Grace and with her ability to learn how to engage with her environments. I surmised this approach to be a deliberate undertaking by Grace’s mother in an effort to maximise Grace’s independence and ready her for her mother’s inevitable absence.

With adjustments made, Grace can be an unremarkable urban inhabitant. By means of self-discipline, in Goffman’s terms (1963, p. 83) she can enjoy her right of ‘civil inattention’. Through modification, Grace’s presence in public places ‘does not constitute a target of special curiosity’; her social behaviour is trustworthy—predictable, reliable and legible—requiring only a glance by a stranger in accordance with the prevailing ‘interpersonal ritual’ of social exchanges (Goffman 1963, p. 84). Unlike her school days, when an atypical reaction might have been triggered by having to walk through a large empty space, or by the stares of others, she can now be acceptably social. For Grace, the modifications made to attain this level of comfort are eclipsed by the benefit, enjoyment and ‘normality’ of being included.

The want for human contact is one defining characteristic of autism that has been repositioned since its clinical recognition by Kanner in 1943. The ‘communication deficits’ and ‘difficulty building friendships’ characteristics of autism (American Psychiatric Association 2013b) remain as symptomatic

criteria, but they have been dissociated from conceptions of preference. Supporting advice and evidence for this correction has been gained from self-advocates and more informally through anecdotal narrative. This acknowledgement, however, has not improved the peripheral positioning of many people. Contemporary discourse and understandings recognise that people diagnosed with autism 'do not necessarily prefer their own company. Yet in spite of their inherent desire for companionship and social connectedness, many remain isolated, lonely, and painfully conscious of the way in which their struggles with communication and interpersonal relating limit their ability to form meaningful relationships' (Autism Spectrum Australia 2013).

Rob is 'painfully conscious' of his inability to socialise in a neurotypical world. From the quiet of his living room, the thought of him being able to contact a friend or initiate an outing was overshadowed by his negative disposition. Rob's school friendship groups are slowly dissipating, and making new friends requires a strength, confidence and resolve that are not available to him.

> I went through some pretty bad depression for quite a few years and that didn't help, I avoided people quite a bit … um … and you know I've only really gotten on top of it recently and even then it's still a struggle so I now make more effort to see people but it's kind of a little bit too late now with my old friends cause they've all moved on and they've gone in different directions. (Rob interview Feb. 2016)

Rob's isolation compounds his anxieties. Of the five participants, his reclusive position showed most profoundly the impact that autistic differences could have on inclusion. He described his struggle to reconcile

his environmental sensitivities and interpersonal difficulties with his need for social and intellectual stimulation. On leaving his house Rob's unique and atypical characteristics are pitched against the much larger, more unified typical characteristics and socio-cultural norms of the neurotypical population.

> It seems to me that like the normal smells that most people just find average things they're just really strong for me, yeah I find it very overpowering very easily … the worst thing is the smoking one, I just can't stand that, so that's one reason why I don't like going on the bus is cause people always smoke at the bus stop (Rob interview, Feb. 2016)

Urban interactions require that Rob constantly concentrate his efforts on self-discipline just so he can locate himself in everyday urban life. The capacity to firstly gain sufficient confidence to breach the neurotypical clique, then to continually maintain a level of comfort while actively combating anxieties and sensory attack, is a distinctly one-sided expectation.

> It's just shocking, it's just terrible, and when I go in there, there can be just like only three people in the whole place and their conversations just kinda echo and its gets too much for me and I can't handle it. I mean I do stay, I don't have to get away from the place but I find it quite stressful. (Rob, interview Feb. 2016)

Relating to people whose experience and understanding of human contact is innately neurotypical, and to places embedded with those understandings, requires that Rob make all necessary adjustments to maintain a level of comfort.

> that's the annoying thing with Asperger's, you want human contact but when you get too much you don't want that so there's a certain comfortable level and generally you never stay in that comfortable level for long. (Rob, interview Feb 2016)

'Contact' is a term that can be qualified by a spectrum of relational possibilities. It can include physical touch, visual acknowledgement, spatial proximity, and mental association. Contact is the essential precursor to an encounter, to connection and connectedness, and can be experienced in unison or separately. It can also occur without the furthering and binding condition of connection. Patricia's peripheral urban encounters for example provide human contact with limited investment in interpersonal interaction, and her recounting of her experiences intimated a satisfactory level of contact. Jacobs (1961, p. 56) contends that in the circumstance of community there is value in all 'casual, public contact'. Wiesel, Bigby and Carlin-Jenkins (2013, p. 2391) refocus the concept of encounter to individual experience; 'Encounter, social interaction between strangers in the urban public realm, are moments where differences and boundaries of inclusion and exclusion are negotiated between individuals, contested or reaffirmed.' These moments, regardless of their depth or perceived significance, are 'meaningful, as they constitute an important dimension of the social life of cities' (Wiesel, Bigby & Carling-Jenkins 2013, p. 2404). These moments all contribute to a person's comfort level and their experience of inclusion.

The neurological and physiological condition of autism can influence all expressions of contact and encounter but the scope of a person's want for human contact, their ability to make contact, and the type of contact needed at any one time, are individual and cannot be stereotyped into typical/neurotypical groupings. For example, Rob is seeking a 'comfortable level' of contact, Andrew is seeking contact with 'normal' people, Patricia's

routines avoid ‘unnecessary’ contact, and each of them seeks respite from contact in varying ways and to varying degrees. The experience of isolation can be viewed as inversely relational to contact. Meaningful relationships and connectedness are the personally ascribed harmonious balance of the two. It is this balance that provides the ‘comfortable level’ Rob is seeking.

Andrew’s want to be social meant that he sought out human contact at every opportunity; he even admitted to growing a beard so that he could regularly visit the barber. ‘I’ve had something like a year and a half now at least since I started growing the beard, going in every week to get it trimmed, and again, it’s the people, the venue’s kinda nice … smallish, not crowded like my room. Friendly, fairly quiet and river views,’ he explained (Interview Jan. 2016, Diary Dec. 2015). The weekly outing provided the contact with ‘normal’ people that Andrew craved. In the barber’s chair conversation is direct and personally focused. It was one part of his schedule that allowed him to be the centre of attention and one of the few places he felt calm, stating, ‘it’s hard when a place like that is built on the river and looks out on the river, it’s hard to imagine a lot of negativity’.

Many of Andrew’s public encounters increased his anxieties about interpersonal contact, limiting his confidence. And, because of the inextricable link that Andrew perceived between the operations of the social environment and the componentry of the built environment, his access to public places was diminishing; disciplining himself to fit in was becoming more difficult. Andrew could not abide noisy and crowded places; he did not use earplugs and had not undertaken any form of tolerance conditioning. Instead he described moments of anxiety and in complete contrast to Grace, transposed the obligation of responsibility for rectification. Andrew described a want to have others modify their behaviour to minimise his discomfort.

> There are situations … when it's like really, really crowded and loud in here you'd like to be able to do like with TV and turn the volume down a bit and um, there are some people in your lives at times you just wish you could press the mute button, it's probably more of a general comment than that specific day and it's probably sort of reflects on my feeling that these are things I need (interview, January 2016)

The place that Andrew wanted to 'turn the volume down' was a small sporting club facility that routinely bustled with people and conversation. Although he mostly stayed on the margin of events in an administrative role as a club committee member rather than club participant, Andrew maintained membership as an antidote to the cloistered carer position he held with his parents. He had been attending events for several years yet still did not speak of other members with familiarity.

> I don't recognise any of them, I'm still trying to link the faces to the drinks, then I'll link the faces to the names, I don't know when I'll get round to linking the faces to the [equipment]. (interview, January 2016)

The difficulties Andrew had in making these connections, and the disconnect that he felt after years of association with the club, align with discourse on autism and cognition, which is discussed in detail in chapter 3. In summary, cognitive work provides pathways to connectedness by not only processing immediately available information, but through the activity of experiential gap filling—by accessing personally stored information that is available by means of association and memory. If experiential information is missing or confused then gaps are not easily filled and there is potential for dissociation

(Section 3.2.3). Andrew's description of his method for linking specific things to members' faces evidences this dissociation. Years of familiarity have not provided him with the necessary gap-filling information and until he can successfully complete the first link, the others cannot be made. The noise and activity of the club likely intensify his connection difficulties, impacting his ability to engage meaningfully. So, when the crowd and the noise become intolerable, Andrew simply leaves the building.

The lapse in Andrew's gap filling might also contribute to an inability to begin new relationships. 'Encounters' with sports club members could be a necessary bridge to a friendship and help to foster feelings of social inclusion (Amin 2006; Bigby & Wiesel 2011). Described as informal 'interactions which unfold in urban spaces. Exchanges that are fleeting or more sustained, between neighbours, participants with shared purpose in a public place, consumers and shopkeepers' etc., the activity of 'encounter' can forge relationships and also expose a person to different types of social interactions that can be built upon for future use (Bigby & Wiesel 2011, p. 265). Bigby and Wiesel (2011) suggest that chance and informal encounters are more consistent with urban life and community formation, and especially important for people who experience exclusion and isolation. Andrew's stepped and linear process of linking names to faces that is devoid of recalled associative information would likely affect this process, impeding the benefit to be gained from his encounters.

Andrew conveyed his experience of overexposure: of staying too long in a challenging environment, of reacting to those challenges with socially unacceptable behaviour, and of the resultant impact on his person and on his everyday geographies. He described meltdown moments—loss of speech, fear, and physical abeyance.

> On Aug 28 2013, yeah, that's a branding in my psyche … I'd reached a point of near terror in the store, and froze at this time. I could only speak in monosyllables, and bluntly, after being bullied into a response. I was even threatened with the police and could not defend myself. I kept hoping I'd have a stroke or at least pass out … To this day I cannot enter the shopping centre and it turns out go into any other Woolies store, I've tried … but it gets harder each time even when I'm with someone. The last time I couldn't find anything and just wanted out. (diary, December 2015)

'How do you fix that?' asked Andrew (diary, December 2015). Andrew's confusion about whether his reactions and anxieties are linked to a definite clinical diagnosis exacerbates his anxieties and he is without practiced methods for alleviation. It is possible that like Grace and Stuart, early diagnosis and tailored conditionings would have provided him with the necessary tools to either avoid or minimise his meltdowns. Intervention therapies are currently prescribed by autism outreach services and promoted to have effective and positive outcomes. Andrew, however, is middle-aged, without a definitive diagnosis, without learned strategies and meaningful behavioural references. He relies upon his only proven coping device, self-exclusion.

I could not avoid being empathetic to Rob's reclusive position. At his age, I surmised, there are social activities he should be enabled to enjoy, choices and freedoms that he should have access to. Yet he was there in his parent's living room struggling to find the next impetus to leave, knowing that if he did leave he would have to work hard to adjust cognitively and tolerate what he encountered, all so he could then decide whether to 'just kinda soldier through it' (Rob, interview, February 2016) or contend with his fight or flight responses. What also became increasingly apparent was the incongruence

between the types of social activities and places directed at Rob's age group, and the specifics of Rob's sensitivities—they were in direct opposition. Rob's hypersensitivities—noises, smells, and crowds of unpredictable people—are typically at the centre of most public socialisation activities for his age group, and perhaps for most age groups. That is, urban public life has focus on vibrancy and vitality and urban public places are most often devised to house and maximise those things.

This paradox of incongruence confronting Rob is exemplified in the research undertaken by Madriaga (2010) and Owen *et al.* (2016), which examined the experiences of students with Asperger's in university spaces. The students' in Madriaga's study described the difficulty they experienced trying to engage in the social life of the university, identifying the student union and the pub as key spaces that provide opportunity for social engagement. The socio-spatial construction of those spaces, however, made them inaccessible and, because alternative equivalent socialisation spaces did not exist, many students withdrew to more isolated, less populated places such as the library, or completely retreated to their dorm rooms (2010, pp. 26-27). Owen *et al.* (2016) found that even the intentionally provisioned quiet spaces provided by a university, such as library quiet rooms, could prove inaccessible for people with autism because the access to those spaces often required travel through areas of high 'sensory furniture' (Davidson & Henderson 2010).

Madriaga (2010, p. 26) suggests that the inaccessibility of social spaces is not only attributable to the repercussions of an actual situated occurrence of a person's sensory overload, but also to self-awareness. Being aware of hypersensitivities can compound anxieties about attempting to gain access in the first place. If a person's autism intolerances can be subdued enough to allow access to places of congregation, there are always other challenges such as the gatherings of smokers identified by Stuart.

> It's something that I noticed especially at university, every single surface that you could sit on outside of a building entrance there were people just lining up … and it was generating this big wall of smoke that you had to walk through if you were coming in or out of a building (Stuart, interview, August 2016)

Stuart's heightened sensitivity to smell, especially cigarette smoke, is not something that can be diminished. 'I've always had an issue with it, it just really causes me to choke up and just escape as quickly as I can,' he said (interview, August 2016). On some occasions, however, Stuart chose to be in uncontrollable and challenging environments, and to even tolerate cigarette smoke. He was aware that his determination might have negative physiological consequences but his drive to participate prevailed. Stuart described the consequences as a partial sensory shutdown, an involuntary default to a type of neurological defence strategy. In preparation for a potential occurrence Stuart provides a warning to his friends, stating, 'this is a thing that might start to happen soon' (interview, August 2016). The 'thing' that he is preparing his friends for is a loss of his ability to communicate.

> There have been times when I've put up with all of those things like with tobacco smoke, you know loud music and bad acoustics and all of that because it's been a situation that I've wanted to, there's been something that I valued about being there … after I've been in those sorts of [loud] environments for a couple of hours I've actually found that I develop a bit of a stutter so it's … yeah it's been very annoying actually, it hasn't made me feel anxious or just afraid of being judged by people or anything like that it's just annoying that I could not communicate, and my

> ability to be involved in a conversation was completely shut down … yeah the kind of stutter it is, is just not being able to form words to begin with, like knowing what I want to say but just not being able to make the sound.
>
> So, do you immediately look for a door? I asked.
>
> No, I found that even taking a break and trying to retreat from the noise doesn't immediately solve the problem, it usually just hangs around until it's all over … I think that particular problem only emerged in the last couple of years, or at least I only started to notice it very recently.
>
> Is that because you're putting yourself into more situations that have that potential? I asked.
>
> Possibly, yeah, and it's entirely possible that I may have been pushing myself in that direction and not really realising how much of a burden it actually was.
> (interview, August 2016)

Thus, Stuart's desire to be part of normative social activity places him at risk of losing his fluency of speech. He suggests that this physiological response is the result of an embodied self-discipline; a practice that he has consciously subdued but that subconsciously accumulates. Placing intellectual drive above his bodily needs and disciplining himself to tolerate the consequences, gave Stuart some space to socialise in environments of sensory overload, but it also came at a cost to one of his faculties.

Rob, however, was neither able nor willing to immerse himself into an uncontrollable, socially and sensorially invasive environment. He instead reminisced the experiences of his childhood, a time when the pull of a family outing compelled him to leave his house. He lamented ‘good old fashioned kind of activities and stuff,’ at places like Launceston’s Penny Royal and Grindelwald, themed resorts that are, ‘designed to be a place to go to do things’ (interview Feb. 2016).

> I think that’s what gets people out, is to do something, cause I certainly don’t go into town, I think oh I just might grab a drink and just sit down for half an hour, I never do that, I know some people probably do but I couldn’t think why. (Rob, interview, February 2016)

These places still exist. Rob’s lamenting therefore was not about the demise of the places themselves, it was I speculate, about his frustration with his difficulty to now access them. It is possible that the nostalgia of childhood distorts his memory of these places as tolerable public spaces—after all they would be filled with strangers, noise, smells and children with unpredictable behaviour—however they were places he would have navigated under the influence of childhood excitement and with the protection and guidance of his family.

Childhood includes relief from a substantial amount of planning decision-making. Now, in his twenties, a decision to leave the house rests with Rob. He chooses not to drink alcohol, cannot tolerate cigarette smoke or diminished personal space therefore finding an age appropriate, theme-park-like enticement is difficult. In an effort to be part of urban life, Rob had tested his capacity to sit down and endure the social life of his local city mall.

> I did once just to see how long I could do it for … It wasn't comfortable … it was a lot of the younger people that are quite noisy and you don't know whether they're being aggressive or what they're going to do and that really heightens my nerves. (interview, February 2016)

The unpredictability of people's actions and reactions is destabilising and challenges Rob's need for order and consistency. Without such stability he cannot contain his anxieties. Now, Rob relies on his hobbies for stimulus. 'Yeah you've gotta have the goal, to wanna buy a can of paint or something like that, it's not just thinking I'll go out,' he said (interview Feb. 2016). The paint Rob needed was for a car he is restoring in his parent's back yard. Buying car parts and equipment, and playing guitar are the few things that provide incentive.

> I do like music stuff so there's a lot of projects and things I like to do, say I wanted some strings or something like that for a guitar, I'd go into town for that but even then I'd kind of put it off a bit. (interview, February 2016)

Rob's outings therefore are mostly errands. Going into the city with friends is not an available option because in that position he is unable to maintain his 'comfortable level' of contact.

> I'm not the kind of person that would go to town with friends or whatever, that kind of stuff … I wouldn't stay long and if it was really bad I'd really try and get out of there. (Interview Feb. 2016)

Like Andrew, Rob did not have formalised conditioning or intervention therapy as a child and, like Andrew, it is possible that disciplines

learned might have enabled greater socialisation. Now however, what is required is significant inducement.

At the conclusion of my discussion with Rob I reflected on the description of autism–having difficulty building friendships, being overly dependent on routines, sensitive to changes in the environment, hypersensitivity to sound and smell etc.—and on the weight of Rob's entrapment. With the routine of school ended, and no job to demand that he leaves home, he is reliant on his own self-discipline. Rob does want to be social but impelling himself to take action to navigate new or even familiar places, and to communicate with strangers is difficult. When he does manage to leave he finds himself in an uncontrollable and unforgiving environment.

Rob, Stuart, Andrew, Grace and Patricia all desire social connection. The type of sociability and the degree to which they seek it are no different to the varied wishes of neurotypical people. To be social in public urban places, however, it is necessary for people with autism to contain anxieties and supress sensitivities and those actions require practices of self-discipline. Again, the types of self-discipline and the extent of control are individual. It is possible that self-disciplines learned while young, such as conditioning training and social readiness practice, can assist with the habitation of public space, but these interventions are merely supressing some of the characteristics autism rather than assisting with a shared social responsibility to embrace these characteristics within a wider spectrum of normal. Instead, an imbalanced paradigm demands that people with autism make attempts to 'fit in.' The architecture of ableism and its inherent constructions of normal demand conformance, so a desire to be social by people with autism means being held to ransom by behavioural norms and expectations and a narrowly conceived built environment.

6.5. Five perspectives on ableism and autism

Participant encounters discussed in this chapter provide an insight into personal experiences of ableist culture. Participants revealed their encounters with ableism and the personal adjustments necessary for their entry and inclusion into both socio-cultural and built environments. Work in this chapter was discussed under the themes of difference, diversity and discipline.

But I'm different describes personal experiences of the construct of difference through the exploration of the ontological position of participants, their experiences of difference and how each person assumes responsibility for adjustment to *normalise* their differences. Personal differences are confirmed by diagnosis, by the direct and implied advice of others, through years of challenging environmental interactions, or by a combination of all factors. Participants describe varied experiences of the difference/ableism construct revealing ontologies that are unique in both the way they manage their own perceptions of difference and those of others, and in the way they engage with the built and social environment because of those perceptions.

And your universal approach doesn't help much provided participant and contextual discussion on contemporary universal approaches used to address the construct of difference. This discussion evidences the narrow understandings and accommodation of diversity and suggests that diversity of experience will be better accommodated by a diversity of spaces. I propose that the provision of spaces within spaces—adjuvant spaces—will accommodate different levels of immersion into both the physical and social environments of shared urban space and that inclusion to those spaces will therefore be better provisioned.

But I want to be social, so I'll discipline myself to fit in describes tactics used by participants to enable their inclusion into social and built environments and suggests there are different ways to be social. Discussion in this section reveals that Rob, Stuart, Andrew, Grace and Patricia all desire social connection. Their access and occupation of public urban spaces however requires a containment of anxieties and suppression of sensitivities and those actions require personally attuned practices of self-discipline.

The work in this chapter exposes the positioning of difference and its influence on the perceptions, perspectives, decisions, and geographies of people five people with autism. It reveals ableist constructions of normal inherent in the built and social environment and evidences the socio-cultural constructs that remove responsibility for the adjustment of difference from the *able* and delegates the requirement to those deemed to be *different*.

Work in the next chapter continues to investigate the scores of participant experience by examining encounter with connection and disconnection through the themes of confinement, construction, and connection. It explores feelings of connection to environment and the methods employed by participants to facilitate those feelings. Discussion in chapter 7 is intended to reveal the foundations of connectedness to evidence approaches that can combat ableism and facilitate more equitable and more holistic access to the shared urban spaces of the built environment.

chapter 7

Through Asperger Lenses
A collaborative score of experience

Part 2 - Connectedness

Connectedness occurs when a person is actively involved with another person, object, group or environment, and that involvement promotes a sense of comfort, well-being and anxiety reduction.

Hagerty, Lynch-Sauer, Patusky & Bouwsema

An Emerging Theory of Human Relatedness

(1993)

7.1. Chapter layout

Work in chapter 6 investigated experiences of ableism. Through the lenses of five people with autism, discussion in that chapter evinced the socio-cultural and built environment constructs that underlie notions of difference and diversity and delegate responsibilities for psychological and physiological disciplines of conformance. Participants described their perceptions and experiences of difference, and how they accessed and engaged in shared urban spaces of the built environment. Their stories demonstrated the epistemological prevalence of ableism.

Participant stories add to discourse that calls for the expansion of the idea of *normal* and for better inclusion of diversity in the processes and practices that shape the built environment. Next, to support shift in the epistemologies of *ableism*, *normal*, *difference*, and *diversity* that affect approaches to the shaping of the built environment, it is necessary to gain a better understanding of what and how connectedness to environment occurs. Connectedness understandings can then inform and evolve the epistemologies that influence the processes and practices that shape the shared urban spaces of the built environment by suggesting how different experiences might be accommodated.

This chapter refocuses the experiences of Andrew, Grace, Patricia, Rob, and Stuart to the subject of connectedness. It continues to address the first two research questions—how do people with autism experience public urban spaces, and how do these experiences influence their everyday geographies—by examining their experiences under the themes of confinement, construction and connection. I explore the personal geographies of participants, their actual and perceived feelings of connection and the way in which they inhabit their world-space: either by means of confinement or

through personally attuned constructions for coping. I examine the importance of environmental connection and the varied ways in which it can be achieved. I discuss both the practice of, and the value in, blurring the social with the built environment through the investigation of people's perceptions of the objectivity and subjectivity of built form. The experiences conveyed in this chapter show how connection is made through the surety of consistency, legibility, reliability and predictability, all things that can make persons—when compared to built form—an unreliable source of connectedness. Discussions reveal that the built environment plays a subjective, animate role as provider, protector and mentor, as well as promoter of diverse and equal human activity.

The chapter starts with the theme of *Confinement* under the title, *Staying at home is easier*. It describes the result of environmental disconnection—the inevitable contingency position of retreat to places where environmental factors are familiar, understood and can be controlled.

The second theme, *Construction*, has the title, *But I can leave home if I disengage and become invisible,* continues discussions of access, revealing additional or alternative behaviours that participants adopt so they can be included into urban places. These discussions are a reminder that being included and being social are intrinsically human.

The final theme, *Connection*, titled, *The built environment is dishonest, and it would be easier if everyone just followed the rules,* is an exploration of the derivation of environmental meaning. It explores personal perceptions of the value and purpose of the built environment, reveals terms of engagement and what is necessary for connection—the social, spatial, and sensorial factors of connectedness. In this section I discuss the importance of rules and of the consistency, reliability, predictability, and surety of shared urban spaces.

7.2.Confinement

Staying at home is easier

Shrouded and concealed under large digital dots is where Andrew and Rob both located their lives. Discussion about the use of the GPS device to track their daily movements generated analogous responses. 'To be honest I don't think I'd have a lot of information to give you, it would just be like one dot on my house and that's it, said Rob (interview February 2016). Andrew responded, 'I imagine your GPS tracks adding a time dimension, the more time you spend somewhere, the bigger the dot. I think the dot centred on my desk will mask all the other data' (email, September 2015). At the conclusion of my conversation with Rob I appreciated his comment, and although using the GPS device was optional and only used by two participants, for Rob it was superfluous. He was generally more static than the calibration of a GPS device could detect, and the daily tracings would be more satellite-influenced than influenced by Rob's movements.

I envisage Rob's dot to be a domed protective bubble of dark tinted glass secured gently over his house and back yard. Inside the dome the ambient music score is congruous with Rob's physiology and he can be himself without too great a threat of discomfort. Andrew's dot I envisage as more condensed, misshapen and fully contained within the confines of his room. It is darker and more closely located, not glass but a thick mantle thrown over himself and his computer. Inside his shelter the air is dense and stilled, the music score soothing and in that place Andrew can take in long nourishing breaths in readiness for the thinner, more unpredictable air outside of his room. Within their personalised, geographically bound dots, Rob and Andrew find comfort. These spaces are places of greater reliability and predictability

where they are able to more successfully balance the demands and expectations presented by their surroundings. Consistent with the lives of the six autistic autobiographers reviewed by Kinnaer, Baumers, and Heylighen (2016) home is 'the one "sanctuary" where they can control as much as possible and can keep everything unchanged, without the intrusion of others'. The sanctuaries of Rob and Andrew, however, are necessarily more coveted and exclusive because they exist within the sanctuaries of others. Beyond their dots, Andrew and Rob are more vulnerable, forced to be more acutely—cognitively and sensitively—on guard.

Replicating these personal loci of safety, or at least minimising the effect of less reliable environments, is the substance of access. Finding spaces, places and methods of admission into more public, less controllable environments is key. Rob's inability to tolerate, or tolerate at length, many of the challenges of urban environments, means that he is mostly at home in his familiar, more controllable place. He suggested that a level of comfort could be achieved through practiced and routine exposure. In section 6.2, I discuss Rob's lack of routine as a contributor to his feeling different, and in section 6.4 routine is upheld as a positive force in the construction of social stories. However, at Rob's current juncture, routine was something currently absent from his life.

> I don't go out very much… What helps me is having a routine, that's the one thing that school did that helped … cause I guess you've got a routine with people you know, it kind of keeps you in practice with social things a bit more whereas where you, like for me at the moment where I'm just kind of a hermit, um when I do see people it's quite nerve racking (Rob, interview February 2016)

Social things—the activity of being social, of spending time in the company of others—and the routine of those social things, are at the root of Rob's anxieties and, in combination with his hypersensitivities, make his experience of the built environment mostly oppositional. The built environment is saturated with both the residual and direct effect of other people. 'It's probably sad to say, but most of the bad things are created by the people there,' Rob said (interview, February 2016). It is other people who make noise, crowd spaces, and smoke cigarettes, who are unpredictable, unreliable, and leave places 'covered in dirt and chewing gum and all kinds of things and graffiti and stuff' (Rob, interview, February 2016). Thus for Rob, even being in an urban space without other people being present can be uncomfortable. The visible—as well as the invisible—human residue can be a deterrent and, once people are added, his degree of discomfort increases.

Discussion in the chapters 1, 2, and 3 argued the impossibility of separating the built environment from the social environment because it is not possible to experience the built environment (its construction) without the direct effect of human influence or the weight of perceived meaning—or, in combination, human residue. As Dovey (2007, p. 1) states, 'As a form of discourse, built form constructs and frames meanings'. Both embedded socio-cultural meanings and a person's experiential memories of place make it impossible for any built environment to be devoid of human influence. In his discussion titled, '*The embodied meaning of Architecture*' (2015) Johnson discusses the human propensity for 'ordering' environments, noting 'the ways we organise space and buildings address simultaneously our need for physical habitation and our need for meaning'. It is this 'ordering of environments' that instates the 'bad things' into Rob's experiences in urban spaces. Ordering occurs with intent, by design, and for purpose. It is the part of the process that can determine whether a person feels welcome into a space or not. It can influence activity and behaviour. To be social Rob is

required to enter into domains created by and for people who do not share his experience or construct the same meaning, into places, and where his control over what happens next is significantly reduced. It is possible that derived meanings may be common or even aligned but not necessarily the same or unified. I asked Rob how far he had ventured and he described several family holidays.

> Generally to Melbourne, I've been to Sydney and when I was a seven-year-old I went to Austria … I don't know how I managed with it actually, probably couldn't manage with it now to be honest, certainly not on my own, that's why I haven't been anywhere on my own. (interview, February 2016)

Adulthood therefore has constricted Rob's world-space. Now, staying at home was easier. We did not directly discuss this change but it was clear that Rob viewed his childhood as a more secure and more supportive time; there was safety in his family's presence and directive in their actions, things that Rob was not able to replicate, things that adulthood expected. Rob was more comfortable under his dome.

Andrew stated the same, 'I basically just don't go places off my own initiative' (email, September 2015) and, while considerably more socially active than Rob, Andrew's outings—besides his special treks into the natural environment— were mostly dictated by the demands of others. Andrew's carer responsibilities required that he leave his house but his parents mostly directed and determined those outings, they were part of an organised weekly schedule. The daily notes recorded by Andrew describe his days in terms of tasks,

> Day 1 - Tasks: Laundry, Mowing/brushcutting

Day 2 –Tasks: Huon Valley errands – haircuts, fruit etc.
Day 3 – Tasks: Hobart errands
Day 4 – Tasks: [club] BBQ
Day 5 – Tasks: Hobart errands
Day 6 – Tasks: Hartz Mountain National Park, Lake Esperance
Day 7 – Tasks: [club] BBQ

> There's the errand day and the appointment day, sometimes dad has medical appointments, which we have to go to but the common fixed places—there's the Coles [ ] where we go to get groceries, um Bunnings we hit fairly often but not like every week (interview, January 2016).

> Mondays are usually "clean" days, due to it being laundry day. This one [Andrew] had to break that rule to get the lawn mowed after adverse weather & other distractions (diary, December 2015)

> There's always a huge list of things to do which is always kind of piled up … Few of the decisions are mine (interview, January 2016)

These tasks, undertaken at the behest of his parents, required that Andrew leave his house; in fact, they required that he leave his room. His daytrips, however, were not random and never impulsive; they were hours begrudgingly spent inside the car and in places steeped with routine and familiarity. Otherwise for Andrew, 'what seems like the typical day is sitting for hours, five or six hours in front of the computer' (Andrew, interview January 2016). Andrew also stated that it was the people, not the structure of public spaces that were a problem for him.

> I cannot see much in the built environment that greatly affects me. But I can see an awful lot in how it is used that can be overwhelmingly negative … every tough experience seems to be not things but people, at least primarily. (Andrew, diary December 2015)

The negative use of the built environment by people that Andrew sees and feels—like Rob's 'bad things'—is part of the built-socio-political construction. There are, however, dual and opposing issues within this construction. The ordering of public environments discussed above, determines the rules of occupation, what is socially acceptable and who is allowed in; that is, it provisions the 'ceremonial rules that govern public spaces' (Cahill 1987; Ryan 2010). People who contravene those rules challenge the established order. For Rob and Andrew—as well as Patricia, Stuart, and Grace—it is the consistent and established order of the places that they choose to inhabit that can provision some degree of access and connection. If people in public places follow the 'rules' then there is alignment of the built-socio-political construction and potential for more positive experiences. 'Yeah, said Stuart, 'it's like anytime I knew there were rules in place, people were supposed to be following them, but they didn't, that, ah that bothered me quite a lot' (Stuart, interview August 2016).

Paradoxically, it is the same rules and ordering of places that can discriminate against Rob, Andrew, Patricia, Stuart, and Grace, by not accepting or accommodating their differences. Andrew himself had contravened the rules and as a consequence his comfortable access to public spaces, at his own determination, was diminishing. The accrual of his public personal conflicts, for which he had little means of resolution, was increasing his reclusion and he was acutely aware of the ever-increasing constriction of his personal geography—his reference to the large GPS dot on his desk for

example, and his description of how he now remained in the car while his parents shopped. Andrew also described how the operational and staff changes at his local Centrelink office had undermined his confidence about being there so he now minimised his visits.

> A few years ago they started telling me to stop coming in as staff were being retrenched … So the first sense was that they were telling me to piss off … and cutting me off from rational people … I tremble if I need to go in there, avoid it as much as I can and get out as fast as possible. I never ask for help, just try and grab documents. You see, my parents make it very hard for me to go there when it suits Centrelink. (diary, December 2015)

Andrew's room was therefore his safe space and when we discussed what his ideal space might be if he were able to create one, he responded, 'a house that meets my needs is healthy and safe' (interview, January 2016), and what that description meant to Andrew was unsurprisingly, that it emulated a space that was perfect for the operation of a computer, that is, 'really tightly controlled air conditioning and humidity and the raised floors and everything the computers need. That's cause sometimes I feel like I do so much work with computers … that's literally the right sort of environment for me' (interview, January 2016). Andrew's ideal 'healthy and safe' environment however would not be suitable for other people; his preferences are individual. Rob did not describe his ideal room or his healthy and safe place, but he did describe the room in his house he had decorated to his liking. 'My room downstairs is full of seventies orange things,' he said (interview, February 2016).

> I haven't gone too overboard with it, like I say, coming back into balance, if everything in there was orange it would be too much

> and I did get to that point where it was a little bit too much so you need kind of neutral things like whites and greys and blacks and things to kind of break it up a bit.

Grace's bedroom was also her art studio.

> I haven't got a proper art studio at home because I mean the studio I've got it's not really a studio, it's really the corner of a tiny bedroom and it's a little bit squeezed in with one small bed, the book shelf there, one doll's cabinet there the walls over there and I was lucky enough to get a desk there. That's what my studio is. (interview, April 2016)

The concept and practice of defining *autism-friendly* environments is, therefore, something that should be debated. These three people with autism are three *individuals* with autism whose preferences for space and place remain heavily influenced by personal likes and interests. Following from the argument about reductive universal design, several decades of research attempting to understand what ideal environments and preferred living spaces for people on the autism spectrum might be also risks losing focus on the autistic individual and, as a result, creating stereotypical place-typologies (Kinnaer, Baumers & Heylighen 2014, 2016). Desensitising environments has the potential to create bland, *beige* built form.

As described by Mostafa (Mostafa 2013), there is complexity in (and debate about) determining suitable approaches to designing environments for people with autism. Most acknowledge the influence of the sensory environment as the prime componentry requiring attention. Mostafa's (2014, p. 143) ASPECTSS Design Index evaluates sensory elements against 'seven principles – Acoustics, Spatial sequencing, Escape, Compartmentalisation,

Transition spaces, Sensory zoning, and Safety'. The evaluation is aimed at architectural application—the design development of the physical componentry of the built environment—and importantly, the approach is acknowledged to be a starting position. If this approach were to be applied to shared urban spaces however, the added complexity of the external environment, plus the addition of the unreliable and unpredictable behaviours of other people, plus instated socio-cultural ableism (discussed in the previous chapter), would likely all work to disrupt and confuse potential positive outcomes. In an external urban environment, the infinite number of experiences that such an approach attempts to address would also mean reduction to a stereotypically beige place-typology.

Kinnaer, Baumers, and Heylighen (2014, p. 175) interviewed eleven adults with autism about how they lived concluding, 'concepts of autism-friendly architecture are not indisputable rules that can be applied straightforwardly, and that one concept may reinforce but also counteract another'. For individuals, they found, competing architectural concepts must be balanced; for each individual there lies a set of competing and complementary components that needs to be reconciled. There is considerable complexity, therefore, in attempting to create a singular space-type for an autistic identity, and what was also revealed was that traditional understandings of what a 'good place to live' might be were often at odds with a participant's view of what is ideal (Kinnaer, Baumers & Heylighen 2014).

Descriptions of the spaces fashioned by Andrew, Rob, and Grace also suggest that, given the opportunity, their ideals might push the boundaries of what is traditionally held to be appropriate, and also of what is consistently held to be appropriate for people on the autism spectrum—a de-cluttered, low stimulus environment. If each of them were to take that opportunity, it is likely the GPS dot on Andrew's desk would grow darker, the dome over Rob's

house would glow orange, and Grace's bedroom would completely transform into an art studio. Disconnection, while having the effect of isolation from shared spaces, is not necessarily answered by the construction of places deemed appropriate by neurotypical others.

7.3. Construction

I can leave home if I disengage and become invisible

Andrew, when it was permissible, defaulted to the ultimate fix for his potential public meltdowns and it was a solution common to all participants, albeit in different forms and to different degrees. Isolating himself from conflict and staying at his desk immersed in a virtual world that he could switch on and off, sustained him. Discussed in Chapter 2, the Internet provides an alternative social environment that is particularly attractive to individuals on the autism spectrum at a 'safe socio-spatial distance' (Davidson 2008, p. 791). It enables a social freedom and control to the user without the oppression of the *ceremonial rules* and the sensory assaults that are pervasive in other public social spaces (D'Auria 2010; Davidson 2008). But Andrew also described a different type of isolation, not isolation in the form of physical absence but isolation in the form of psychological abstinence—being present physically but limiting his exposure mentally.

> You know like you have to close yourself off particularly when you're in big cities, sort of like you have no personal space physically, but you have to sort of like project it and shrink in. (interview, January 2016)

Projecting and enlarging his proprioceptive awareness and, at the same time, shrinking and conserving his psychological self in order to protect his

sensitivities, is what I understood from his statement. Having to shut down or minimise one or more components of neurological processing so he could tolerate being on a busy city street is not unique to Andrew, but it is a typical human response to stimuli overload. The process of directing attention to enable focus on a task or situation is essential to cognitive functioning, and being able to ignore irrelevant stimuli while focusing on necessary and meaningful stimuli is critical to that process (Bogdashina 2003, p. 101). Bogdashina (2003, pp. 83-102) posits that this process of directing attention can be different for people on the autism spectrum where, as a defensive strategy, it can operate at an excessive level and lead to a problem of having a focus that is too narrow and extend even further to an extreme of 'mono-processing'. This narrowness may engender an intense focus on one thing at the expense of contextual information, or cause a complete disengagement of some senses, or cause intense concentration on others. It was likely that this is what occurred when Andrew froze and was reduced to speaking in mono-syllables, and when Stuart's speech was reduced to stutter, and also what was at the root of Rob's reclusiveness when, because the management of his sensory overloading required intense and dedicated focus, he chose to avoid confrontation and stay home.

This process, however, can also be constructed as a strategy for engagement. Andrew's practice of *closing himself off* suggests a deliberate action to minimise bodily intrusion and maximise necessary function. Stuart also, on regular occasions—when the objective was not a valued experience like the bar room described earlier but a routine activity—actively employed a direct method of coping with overwhelming sensorial stimuli, one that did not affect his ability to speak but did involve the diminution of other senses. He described this device as a fix to his overexposure; it was a method for partial disengagement with the environment. Stuart actively directed and constricted his sensorial attentions, a technique he had started using at a

young age, one that had now become for him, a normal and instinctive response.

> yeah the crowds and all that, that doesn't really bother me, I've found that when I'm walking through any sort of city I guess, I'm sort of able to kind of switch off and like disengage and sort of become invisible … whereas, if I felt like you know people were paying attention to me and watching me and all of that, that would be a quite a lot more pressure.
> (interview, August 2016)

It is a device that directs neurological and physiological energy toward one sense, or problem, and reduces input or completely withholds it from others to relieve discomfort, anxieties or even pain caused by overload. It is, therefore, also a device that can facilitate a person's status of civil inattention by removing the potential for revelation of different public behaviours. Correspondingly, because of the withdrawal of energy or input from one or more senses, it is a device that will have corollary effects; some of them minor, personally bearable and outwardly unnoticeable, but depending upon the intensity, length and type of shut down, some can be major, personally tormenting and cause behaviours that will increase the likelihood of civil *attention*. For Stuart this tactic did result in an interruption to his perceptive processes. He lost his ability to recognise faces, something that was not problematic when in the presence of strangers on a public street but a happening that could cause minor issue with family and friends.

> There have been occasions when I've been so tuned out that I'm not really paying attention to people's faces, I'm only really noticing the body language to do with where they're walking, so there have been occasions when I've completely missed someone

> that I knew in the street … so it's like this whole facial recognition thing is just dormant and not looking out for people to recognise or say hello to so even like close friends and family I've completely walked past them without noticing… it happens wherever I go. (Stuart, interview, August 2016)

Stuart's explanation of the impetus to his 'switch off, disengage and become invisible' response is suggestive of the need to consider the existence, construct and workings of a higher order, collective human sense. When asked if he could identify what it was specifically that he was switching off to, Stuart responded,

> I guess the sense of readiness, the readiness to respond … like when I just sort of zone out and forget that I don't need to focus on being social or paying attention to people … that has always relieved me of the need to be on guard and ready to respond at a moment's notice. (interview, August 2016)

At the expense of facial recognition Stuart was able to shut down demands on his social readiness. By removing his engagement with aspects of the animate environment he could minimise cognitive exhaustion. His described 'sense of readiness' could be reduced from a combination of the full complement of human senses down to the incorporation of only those senses necessary for the specific task at hand, a survival tactic typical of many innate biological environmental responses. 'Being I guess anonymous in an urban environment just sort of, I guess it kind of gives me a sense of safety I suppose ', said Stuart. It was a construction that enabled his presence in public places and a different way to be social.

For Stuart, positioning his want to participate above his comfort level had become routine, but he recognised that this was not possible for others. He had studied university level clinical psychology noting, 'learning about all the things that can go wrong with people is pretty distressing' (interview, August 2016) and he had worked within schools with children on the autism spectrum. At the time of our correspondences Stuart spent much of his time—for both work and leisure—in a technology innovations hub. He recognised—in line with the propositions of others (D'Auria 2010; Davidson 2008; Grandin 2009a; Silberman 2015)—that the field of information technology was a refuge space for people with Asperger's. 'It's where you know, tech enthusiasts and people who build things from electronics and program games and apps and things like that, they can sort of get together and you know just work in this little space, yeah build things together', said Stuart (interview, August 2016). The people in that place had found their reason to go out and the place they inhabited was like a lily pad offering a safe haven and resting place amid the swirling waters of the urban pond. It was an intermediate space: semi-public, semi-social, a place filled with like-minded people whose tolerances and intolerances were more often aligned, and where the ambient music score was likely harmonious. It was a place similar to Grace's art-room, without formal support services, and with an increased level of individual autonomy.

I had the opportunity to visit the hub on Stuart's invitation. It was a hive of creative and varied activity, a place where my presence was barely acknowledged. He excitedly showed me through the computer-filled rooms, describing the projects of the occupants and elaborating on the possibilities that the field of information technology offered. Stuart revealed his aspiration for technological inventiveness to be a remedy to the isolation challenges of people with autism. He talked of augmented reality and assistive IT hardware, and he radiated both empathy and fulfilment when he

conveyed the story of the trending Pokémon game that was positively impacting the lives of many young people with autism.

> Incidentally, over the last few weeks you've probably heard a lot about the new Pokémon game that's out … I've been having quite a lot of fun with those, same as a lot of my friends … yeah I've got a lot of friends that have quite a lot of anxiety and depression issues of their own and this has just been this fantastic thing to just get out and socialise with … augmented reality, it's closely tied with virtual reality but it's added to the real world rather than replacing the real world and that, both of those things, virtual and augmented reality, they I think are very close to transforming everything. (interview, August 2016)

Stuart's conception of 'transforming everything' was a positive eventuation. Augmenting reality meant that life could be improved. Missing information could be added, confused information could be clarified, and all in a way that would be tailored to individual requirements. Like the Google Glass glasses he described that could offer wayfinding and facial recognition for people with autism, augmented and virtual reality harboured opportunity for differences and difficulties to be quashed. At the time of our discussion, this technology already had application with autism as learning and assistive apparatus and, as with all technology, there is continual refinement and rapid advancement. (Goldsmith & LeBlanc 2004; Howorth *et al.* 2019; Samir Abou, Osam & Vladimir 2019). What is also significant about technology-based assistance is that it can be seen as commonplace and unidentifiable as an aid and, 'not result in children with autism standing out from the crowd, but rather, blending into our more technologically advanced society' (Goldsmith & LeBlanc 2004).

An Internet search will today supply a multitude of advice and information about virtual and augmented reality applications by and for people on the autism spectrum. This is in addition to the incalculable number of organisational and independent web and multimedia sites offering formalised and informal advice and support. The pros, cons, benefits and detriments of such technology are not a relevant subject for this thesis. However, what was evident was that the assistance found by Stuart and his collaborators in the IT hub was positive; it was a successful construction of an adjuvant space. Stuart's story continued with enthusiasm, promoting one success of the technology and suggesting that this result in itself was success enough.

> There was this mother of an ASD kid who just said that all of a sudden, now that her kid has this game in his hands, he was socialising with other children and adults, and it was just this miraculous thing for her … it was like an adult just tells him, 'hey there's this one just around the corner, go get it' and he would look up at them, look them in the eyes and say 'thank you' and smile and all that, that was an entirely new thing for this kid and his mum was just not sure whether to laugh or cry.
> (interview, August 2016)

It was possible, I thought, that a similar place to Stuart's technology innovation hub, if it were music-focused, might offer Rob a safe alternative to his home and provide him with a more socially active and nourishing environment. Such a place might provide him with the necessary impetus to leave. Of course, it still may not be enticement enough to eclipse Rob's susceptibility to sensory overload. For some people, even the inducement or ability to stay in a place of support requires the assistance of diversionary or desensitising devices such as earplugs—as occasionally worn by Grace—to

diminish noise, headphones full of alternative favourable sounds, sunglasses so that others can't make eye contact, a favoured object to distract focus, or specialised stimming items to concentrate energies. For the other participants, motivational stimulus can sometimes outweigh sensorial sensitivities and it is possible for them to temporarily alter their levels of acceptable exposure to the environment or to navigate alternative avenues of access to it, but this exposure can have negative repercussive or counter-balancing consequences such as those discussed earlier.

Grace employed her own unique method of trying to address the eyes she felt boring into her back during school assemblies (Grace's mother, interview April 2016). 'I always had this huge thick fringe, which I found an advantage, well to hide from all those prying eyes back then when I was only a child and up to high school,' she said (Grace, interview, April 2016). Her fringe of thick hair, purposefully grown and strategically cropped, protected her eyes and somehow protected her vulnerability. It provided her with a means of moderating her anxieties. I pictured Grace in her primary school hall on the threshold of the assembly group—a position that offered an easy means of escape—sitting cross-legged on a carpeted floor, head tilted forward, thick fringe obscuring her eyes, a still and focused figure waiting intensely for her timed drill to end. Without the added protection of her bodily veil it is likely that her conditioning training would have been more challenging and the process of *normalising* her tolerances more drawn-out. Grace's fringe provided her with a physically insubstantial yet psychologically powerful construct, which she kept until she finished high school. 'I think as soon as I was sixteen, from sixteen onwards I decided to have my hair shortened' she said, 'yeah, I just got sick of the big, I got rid of the big fringe' (Grace, interview, April 2016).

‘Getting out and doing things is good’ said Andrew (interview, January 2016) but the capacity to do so was not always present. It was not that he did not want to leave his bedroom or that Rob did not want to leave his house, rather, these places—their digital dots of security—offered refuge. When not undertaking scheduled activities, Andrew’s anxieties and lack of confidence keep him in his bedroom with his fifty years of belongings and a portal to the World Wide Web. Rob’s anxieties, sensitivities, and lack of routine keep him under his dome, moving between his room of orange decor where he tries to keep the balance between his obsessive collecting and his need for ‘a certain level of unclutteredness’ (interview, February 2016), and the backyard that houses his car restoration equipment. Staying home was a decision made for them. As discussed above, however, their refuges are part of another domain of control, that of their respective parents. The inability to satisfactorily subdue anxieties and sensitivities, and the ability to override their embodied decisions was dependent upon conditioning themselves through repeated exposure, establishing routine, using self-distraction, or more forcibly, by the directives of others. On errand day he even used the act of driving through city streets rather than circumnavigating via the highway as a method for combatting his isolation.

> I try and vary it … I like to go straight through the middle of the city sometimes, even when there’s no need, because frankly it makes me feel less isolated from the community, which is something I can feel a **lot** at times (interview, January 2016)

Rob is also a driver and he recognised that driving provided opportunity for extraction, a way to remove himself from the safety of his home and a means of access into more public places. He regarded it, therefore, as something he should do, but driving for Rob was daunting and he lamented his lack of confidence. He described his experience of gaining a licence as a ‘long slog’

with his learner-driving period expiring twice. Regrettably the act of driving included challenges that overwhelmingly outweighed the security offered by his car.

> I am a bit of a nervous driver I think … I find it very stressful to start with and then the less I do it the more stressful it is … I haven't been driving for a few months, I went out just a couple of days ago and found it a little bit stressful, um so I'm trying to push myself to do a bit more again. (interview, February 2016)

Rob and Andrew recognised their private vehicles as a personal space that offered a level of security, a buffer between their vulnerabilities and the sensory overload of the environment. A car is a cocoon that provides privacy, comfort and safety that is both spatial and temporal; it partitions and protects its occupants from the outside world (Hiscock *et al.* 2002; Kent 2015). Kent (2015, p. 741) states that the 'car is conceptualised as one of the last bastions of private space in the modern world'. It is devoid of strangers, devoid of surveillance, allows people to be themselves, and does not compel interaction with others. In a study of people with autism in higher education, Owen *et al.* (2016) reported one student's use of their private car parked in the university parking lot as a type of 'informal support'. Parked in a space partially screened by trees, the car was used by the student as a personal haven, a safe place of retreat for recalibration. This informal support space chosen by the car owner offered a degree of separation not available elsewhere on the university campus. Importantly, it also offered opportunity to increase the degree of separation at the direction of the occupant and within the continued protection of the cocoon.

A personal vehicle is a mobile transitional space. Within the cocoon there is opportunity for personal reflection and restoration. In his study of the use of

cars by social workers, Ferguson (2009) describes driving time as ‘therapeutic journeys’ for both the workers and their clients. He suggests a notion of the car as ‘contained freedom,’ a ‘fluid container’ that allows ‘transitional participation.’ The car, therefore, is apparatus that provisions protection, freedom and access. It is an avenue to connection at both practical and social levels. For those people on the autism spectrum who can manage the sensory and cognitive challenges of driving, a personal car can mean access to social worlds that would be otherwise unavailable. As Andrew described, even being in the city streets inside a vehicle offered a degree of contact and being positioned behind the wheel enabled him to regulate his level of exposure. Rob, however, needed his ‘can-of-paint impetus’ to get him into his car and most of the time even that was not enough enticement; the challenges to his senses were too great and, as he described, the less he does, the more stressful it is. Like the daily routine that is keeps Rob out of ‘practice with social things,’ his driving inaction is also compounding.

Stuart owns a car and uses it as his primary means of transport and access, but he suggested the activity of driving might include an element of risk. ‘If my family’s anxieties have any valid basis, it would be about the potential for sensory overload and lack of spare attention,’ he said. Stuart’s Asperger sensitivities, especially his retreat to mono-focused attention that occurred as a response to sensory overload, were ever-present and he conceded to his parent’s concerns stating, ‘it’s still kind of intimidating to be in control of a fast-moving few tonnes of metal, to say nothing of having to be vigilant of others and negotiate traffic’ (email, 24 August 2016). Stuart’s driving, however, was a conscious effort to combat isolation and for him, the autonomy and self-sufficiency that his car offered outweighed his fears.

Stuart lived independently and worked as a freelance graphic designer and illustrator, which also allowed him to regulate his level of social contact, but

the ever-present risk, to which he did not want to succumb, was moderating his exposure to others and to public places to the point of isolation. 'Ideally, it'd be great if I could get anywhere on foot, by bike, or by public transit, and there were places I could rest in the middle of a long day without needing to keep my social readiness switch on' (email, 24 August 2016) he said, but the balance between his driving anxiety and his social contact anxiety was tipped by his want to remain socially active, and it was enabled by the safe space he found inside his car. Like Andrew, Stuart was able to moderate his social contact and the demand on his 'social readiness switch' from his driver's seat.

Stuart's prerequisite for rest was, as he described, a break from being ready. It was not a rest from physical exhaustion but a cognitive rest from cognitive exhaustion. For people with autism, over stimulation and the attentional demand necessary to carry out routine activities can quickly expend cognitive energy resources, and without the ability to rest, retreat or counter the demand, the potential for an unfavourable reaction is increased. The type and length of rest required is of course specific to the individual and may vary from a moment of quiet to a lengthy, sensorially reduced retreat. As discussed in section 3.4 it is a commonly held view that exposure to natural environments can be nurturing and restorative. Kaplan and Kaplan's Attention Restoration Theory (ART) (1989; 1995) proposes that restorative rest can be gained by directing attention toward natural environments because they have the characteristics necessary for stress relief, that is, they are more compatible with human functioning and, therefore, require less effort to cognitively process.

Joye (2013) further investigated the fascination component of Kaplan and Kaplan's ART theory, examining each of its three dimensions—attentional bias due to attraction, reduced cognitive effort and the experience of

pleasure—and confirmed the positive effect of natural environments through fascination. It was also suggested by Joye (2013, p. 1) that it is not until a cognitive task is 'sufficiently difficult' that the effort dimension becomes important. For people who are cognitively in tune with their environment the routine processing of information and the need for rest from it will be minimal. For people with autism, however, the potential for cognitive difficulty will be great, requiring increased effort to process information and making the need for rest and restoration opportunities more critical.

With specific reference to autism, Davidson and Smith (2009, p. 898) suggest that restoration is most often provided by 'more-than-human' encounter, or 'natural world' experiences, and they propose that these events can establish a meaningful and rewarding form of social relationship, that is, that a type of sociality can exist between a person and the environment. Social interaction or being social, therefore, does not have to consist solely of human counterparts. Emotional attachments can be formed with non-human components of the environment and for people with autism these relationships can be an invaluable restorative resource. Andrew stated that he needs natural environments to 'feel positive' (diary, Jan. 2016); Grace described her preference for walking through the bush rather than on the street because it was more 'beautiful' and 'peaceful' than the street (diary December 2015, interview, January 2016); and Rob explained his preference for 'natural spaces' that are less crowded, quiet and devoid of strong smells. He recounted his routine retreats to the park to find a place that would ease the constant overloading of his senses.

> I've done a few courses in town and that's generally where I go for lunch and that seems to even me out a bit … yeah I like to go there, it's got heaps of seating so you don't have to sit next to someone. (Rob, interview, February 2016)

Stuart, however, did not describe his rest space as anything more natural, less people-centric, than any another and he also described experiences of cognitive overload in natural environments where there were no other people present: 'it happens wherever I go, even when I was living in a fairly rural area, taking one of my dogs for a walk' he said (interview Aug. 2016). Instead, Stuart described resting in urban places, in both places that were intimate and contained, and wide open and less crowded.

> When I've been over in Melbourne or Sydney sometimes I've just sort of retreated into a little café or … even at train stations I guess, yeah you know there are often some areas that people rarely go to because they're not so easily within walking distance. (interview, August 2016)

These spaces offer Stuart reprieve from unpredictable activity and social demand. Being able to step out of the flow and intensity of a city street, if even for a moment, can provide the recovery necessary for stepping back in. A café can be a restful and safe place not only because of its containment and sheltering effect but also because of the predictable activities that take place there; there is an expected socio-cultural behavioural activity within the space, and typically, a predictable architectural layout to support that activity. In that space Stuart knew what to expect and importantly also, what was expected of him. And, with even further refinement of his positioning within the space, he could rest his readiness. 'When I am choosing a place to sit down in a public place or even indoors, I tend to prefer going to like an inside corner, and I think that's because that way I'm back up against a solid surface and I can see everything around me' he said (Interview Aug. 2016). From this position of surveillance Stuart's personal space is more defensible and his feelings of safety are improved. His attentional functioning therefore

has even greater opportunity to rest and restore, preparing him for re-entry with a heightened state of readiness.

Stuart's ability to find spaces to rest in urban places does appear to contradict his statement about using his car—rather than travelling by 'foot, by bike, or by public transit'—because of needing rest from his social readiness. The important point, however, is that travel by car relieves him of having to seek out places for rest. The cognitive activity—directed attention—required for the search of a rest space can be put toward positive activity and the moment of search-anxiety can be completely avoided. Stuart is in control of his car's availability and in control of its degree of exposure—in the city, on a side road, windows up, doors open, radio on, sunglasses on, or driving home. The availability of such defensible, refuge spaces in an urban place is not guaranteed and even if they are familiar, Stuart has no control over the activities of the other users of those spaces. When combined with the uncertainty of when, where, and how much he might need to step out of the urban flow to restore his readiness, Stuart's car is his preferred apparatus.

Feeling safe, or knowing that there is ready access to safe places, expands a person's prospects for entry to urban public spaces, increasing the degree to which they can be social. The location and characteristics of a safe place will vary with the person. Even within the context of the built environment, a safe place does not have to have material property. Rather, a safe place can be a cognitive construct. It was clear, for example, that Patricia maintained preference for particular urban locations and that she inhabited some places more comfortably than others. It was possible that she did not confide anything about those preferences or about particular places that might ease her discomforts because of her objective and impersonal manner. The alternative, however, is that the true location of Patricia's safe place is not

material but is instead a psychological positioning. Like Stuart, Patricia's occupation was freelance and her social contact was correspondingly regulated. Her working time was spent buried in library research, taking online classes, and pursuing her photography and blog writing hobbies. She also volunteered at a museum two days per week. The subject of her museum work, however, did not feature in our discussion. It was Patricia's routine transit between her home, the museum, the library and shopping centres that took precedence, and what she explained of these journeys was a wholly independent and self-sufficient undertaking.

Significantly, however, although Patricia's daily journeys were a continuum of public interface, she moderated her level of environmental exposure to keep random and unpredictable social contact at bay. Her exposure was routine and her interactions with people were limited to direct, short and predictable exchanges. Our interview interaction—described in Chapter 5—revealed her discomfort with interpersonal contact and communication, especially that which was new and unfamiliar. However her willingness to participate in the research study at all revealed that her social anxieties could be occasionally quashed to tolerable levels. Patricia presented both sides of the participant dichotomy discussed by Davidson (2010); she was assured enough to participate but not self-assured enough to participate to the extent that she divulged or reasoned personal accounts of her experiences. Davidson states that the 'ASD authors' published in her qualitative study of autobiographical texts 'are certainly not representative of the majority of those on the spectrum' because they are willing to divulge their personal accounts:

> ASD authors belong to a significant minority who have negotiated their way to a point in their lives where – while still on the spectrum – they possess the substantial skills and coping

> tactics required to manage at least partial involvement with the world of others. (Davidson 2010, p. 306)

Patricia did possess those substantial skills, but she did not participate nor write to divulge or impart her experiences of Asperger's. Whilst her willingness to be part of this research study set her apart from others, it required rigid maintenance of her personal space both in text—her research diary, narrative, and emails—and in person.

Like Stuart, Patricia appeared comfortable in her honed social world-space and this locus impacted the nature and depth of the subjects we discussed; she did not personalise her experiences in terms of emotive or sensorial response, rather she externalised them mostly to the point of how they might impact others. The narrow footpath with telephone poles down the centre, for example, was a concern for others who might 'have a pram or something' (interview, August 2016), and the traffic lights that operated independently of human input were a hazard 'if you happen to be really slow [or] an old lady with a walking stick' (interview, August 2016). Patricia did not make any statements about how her personal experiences were different to others. This existential territory of world-space consolation is the corollary perspective previously described in the *Reflexive Comment* Section 5.5.3 as an underlying challenge for this research, and discussed further in the concluding chapter. Patricia was acutely aware of her world-space and her safe place was that exact knowledge—in knowing exactly where it lay and in the activity of maintaining a clear division between what was to be socialised and what was not.

Rob's expression of his socialisation adeptness was a complete contrast to Patricia; he did feel different and he did feel socially reclusive. Throughout

our discussion he referred to his sensitivities and idiosyncrasies as problematic, overwhelming and symptomatic of his reclusiveness.

> I'm not the kind of person that would go to town with friends or whatever, that kind of stuff … I'd find that a little bit stressful … I'm comfortable with people I know and comfortable with small groups, say up to about six, but more than that I start to get stressed, I start to get increasingly nervous … there's two main things that stress me out and that's loud noise and smells, I'm very sensitive to those two things (interview, February 2016).

However, even with this constant barrage of sensorial assaults, Rob made attempts to test and challenge the boundaries of his tolerances. 'I think some things are good for you to do more of, so testing my limitations is good for me but I don't like doing it,' he said (interview, February 2016).

Rob had been intermittently employed in short-term positions since leaving school. His current loci, however, made the prospect of anything of permanence seem unachievable.

> I've had a few short jobs around the place but the most recent one was in an office for three months last year … it was good I enjoyed it, again I was very anxious to start with and it took me quite a little while to get used to it but then and once I did I really missed the place, it always seems the way that when I get started with somewhere it just ends and then I have to start a new place and that's very stressful to have to keep changing all the time… I'd just like one regular job which I could keep you know, yeah that's what I need and people have that, and I think, oh why couldn't I have that. (interview, February 2016)

According to the American Psychiatric Association (American Psychiatric Association 2013a) one of the defining characteristics of autism is that 'people with ASD may be overly dependent on routines, highly sensitive to changes in their environment'. It is the activity of change, therefore, not necessarily the subject of it, that has the potential to cause discomfort and stress. For many people on the autism spectrum, the associated anxieties can begin with the idea that change is a possibility, long before the activity is in sight. This resistance to change can be so powerful that the activity of maintaining environmental consistency can in itself become an obsessive, emotionally and physically exhausting routine (Davidson & Henderson 2010). When such activities are combined with the actual presentation of change—or the possibility of one—the result can be completely disabling. For Rob, this process caused much of his anxiety and kept him at home. As he stated, it was the routine of school, of understanding the associated procedures and what was expected of him that enabled him to leave his house each day, and when that routine ended any new outing became subject to the pathologies of change. Rob also made several emotive references to the futility of changes to the built environment. For him they were most often unnecessary and illogical, and they were undoubtedly a source of irritation.

> I think a lot of the things that this Council does … is focused on change for the sake of it and I'm not really sure how much they think about how to improve things, cause a lot of the time their idea of improving something isn't really my idea of improving anything … I mean there's no reason we have to do away with the past just to change to something else. (interview, February 2016)

Although Andrew's days were mostly consumed by routine activity, he openly yearned for the prospect of change. He felt trapped by his carer role, restrained by a lack of both physical space and decision-making freedom, but it was primarily the paucity of understanding about his autism-related anxieties, hindered by his lack of confidence and self-organisation, that he wanted to alter. 'I've been in a "place" for years where I seem to have to over think things,' said Andrew (email, 29 September 2015). Andrew disclosed experiences of significant emotional response to change, one in particular, his Centrelink experience discussed earlier, revealed the turmoil of his anxieties and the extent of understandings he needed to foster. It was an episodic story that punctuated several parts of our correspondences. It explained a series of change-related events at the Centrelink office that he transformed into personal, emotional and psychologically challenging anxieties.

> the consequence was that I found the place intimidating, and cut back going in. Later after the sackings, I now find the place more scary. It was all lit up, all the shutters raised, and often fully staffed. Now, its maybe got one shutter opened, almost no staff and they don't seem to turn on any lights … It does to my mind look darker … it just looks uninviting now … kinda like a cage I guess, and um kinda like controlling you to go in through here rather than you can just wander in wherever it suits you … you never seem to be able to see the same people anymore, certainly not the ones I felt comfortable and safe with … Not real nice to feel the emotions of such a change…. I fear what might happen if I am ever required to notify them of changes to my situation. (diary, December 2015, interview, January 2016)

Finding a reason to leave the house was not problematic for Grace. ‘I never want to be kept in the house for long’ she said (interview, April 2016). Grace described her life as busy, a mixture of art classes, volunteer work and excursions, and it was her determination to participate in those activities that motivated her and enabled her sociability. She commented on the ‘nice sociable background’ (diary, April 2016) of the shopping mall, talked about chatting to people on the bus, asking questions of the bus driver, asking friends to visit the museum with her, shopping in alleyways and borrowing books from the library. Even as a non-driver, reliant upon the public bus system, Grace navigated and found her way, always willing to broaden the geographic area she covered to accommodate her interests. While the bus network did define the parameters of her independent access, Grace’s drive to learn more about art and her eagerness to participate in organised activities encouraged her further afield and challenged the bounds of her tolerances.

> We’ve been to a county fair, we’ve been on weekends away, we’ve been doing mainland holidays recently, and sometimes we go to a sports centre … some of [the others] are a bit loud of course well because I have sensitive hearing so sometimes they can be a little bit loud (Grace, interview April 2016)

The ‘we’ Grace is referring to is a group organised through a support services program. The framework of organised activities and tailored group programs provide a safeguard for Grace, one that allows her to explore beyond the familiar places of her childhood. It was a dedicated learning activity through the support service that taught her how to use the public bus system and gave Grace that much-valued means of access to her independence. ‘They gave [Grace] a challenge, she had to catch a bus somewhere she’d never been before, take photographic evidence, then go back again’ said Grace’s mother

(interview, April 2016). I asked Grace if she ever chose to go into the city by bus, independently, without the draw of an organised activity:

> Well sometimes it depends on how free, what free time I have, what's available and stuff, so basically if I wanted to do craft things for cards and things or something, wellbeing an artist it's nice to do cards, maybe some little bit of home-made presents and stuff like that. (Grace, interview, April 2016)

> Or if something's coming up like my birthday or Mother's Day she'll catch a bus into town and go off shopping and then come back … she's really good at finding her way around.
> (Grace's mother, interview, April 2016)

Grace's confidence and independence to navigate to and within the places she is familiar with is now allowing her to be a guide and chaperone to others. 'If there's a good exhibition on I'd go with a friend, I've made a few friends recently … and one of them's an artist herself and loves history herself, so I took her to there because she was fascinated' she said (interview, April 2016).

With the aid of earplugs Grace's sense of social readiness provides her with a sufficient compliment of senses that enable her activities. It is not possible for her to physiologically shut down or to even reduce auditory input and she did not choose to disengage but instead moderates her contact.

Movement beyond safe places of choice into uncontrollable shared urban spaces requires the assistance of personalised constructions. Constructions vary with individual need, preference, availability and accessibility, and can be either conscious or subconscious actions. Andrew, Stuart, Grace, Rob and Patricia have formulated their constructions to either accommodate their

daily activities or to attempt to enhance their daily activities and routines in efforts to combat feelings of isolation. As Rob noted—and as discussed in the previous chapter—having a routine or working toward establishing a routine, 'keeps you in practice with social things.' Pursuing his hobbies is a conscious effort made by Rob to try to place his wants above his anxieties. Grace's constant pursuit of art-related interests and the support services programs she relies on construct a network of opportunity for urban space activity and socialisation. Her use of her fringe of hair to hide 'from all those prying eyes' was a construction she was able to abandon when she gained more confidence and no longer had to sit in school assemblies. The private vehicles that Andrew and Stuart frequently use and that Rob wishes he used more often, construct a space of retreat and restoration as well as a mobile adjuvant space from where isolation can be challenged. Stuart also suggests that a technological construction of augmented reality might be the answer for people with autism. Tailored assistive technology could construct a semi-virtual, semi-real world that will provision less challenging access to urban spaces.

Constructions can also be psychological and within that domain they can be activated consciously or subconsciously. Andrew described how he can 'close off project it and shrink in' and Stuart described how he can 'switch off, disengage and become invisible'. These actions increase access and allow an operation—possibly at a reduced level—in busy, noisy, crowded and unpredictable urban spaces. Patricia's psychological construction is the maintenance of her personal space. Whether the application is conscious or subconscious is indecipherable but it is a construct that allows her to undertake her daily activities confidently and independently.

7.4. Connection

The built environment is dishonest and it would be easier if everyone just followed the rules

The construct of nature or natural form has long been considered to be 'a creative or compositional grammar' that can be applied to the built environment (Joye 2007). 'By encouraging architects to integrate natural forms and patterns in their work, they are motivated to study nature's shapes and compositional rules, and this can enrich their creative curriculum' (Joye 2007, p. 310). Natural environments, Andrew said, are different to the built environment because they are 'more honest' (interview, January 2016). What can this mean? Is there such a thing as honesty and therefore dishonesty in our environments? How can the built environment be deceitful, untruthful, fraudulent or corrupt? Is Andrew's statement perhaps analogous to Sullivan's much discussed 1896, *form follows function* adage?

> It is the pervading law of all things organic and inorganic, of all things physical and metaphysical, of all things human and all things superhuman, of all true manifestations of the head, of the heart, of the soul, that the life is recognizable in its expression, that form ever follows function. *This is the law.* (Sullivan 1896)

Sullivan's *law* is of practicality, of understanding purpose and limiting form to the manifestation of it, but it is also about expression. Andrew explained his law of environmental honesty as remedy to his life.

> What I seem to need to be positive is a more natural environment. This isn't just trees and rocks, but things that are rational, necessary and not excessive or flamboyant.

(diary, January 2016)

A less natural environment, therefore, or unnatural form, is for Andrew composition and componentry that does not make logical sense in terms of its usefulness, or that includes superfluous elements, or that expresses only the extravagance and whimsy of the designer. For Andrew, the built environment is dishonest because it can appear to be irrational, unnecessary, excessive and flamboyant. But mostly, for Andrew, unnatural form is a construction within which he cannot recognise himself. In Sullivan's words, his life is not 'recognizable in its expression.' With his access frequently deterred by the *dishonest* appearance of the built environment, Andrew is often alienated from purpose and as a result he limits his exposure. On the last day of his fieldwork Andrew took himself to a place of restoration; he went bushwalking, describing it as a much-anticipated and much-celebrated event;

0. 19 Dec 2015, Saturday
1. A very different day, a goal to achieve
2. Tasks: Hartz Mountain National Park, Lake Esperance
3. Outdoors based
4. Good Places: The Park!
5. Bad Places: none

Typical day: No way! I set out to climb Hartz Peak…Only made Lake Esperance…Good Fun! (diary, December 2015)

On no other occasion during our correspondence did Andrew convey or display such exuberance. The openness and the honesty he derived from being immersed in a natural environment filled him with positivity, something he admitted struggling with on all other occasions and in all other locations. The form and componentry of the Hartz Mountain National Park made sense to Andrew and in those surroundings he could recognise himself.

Patricia's commentary on the built environment was similar, although not couched in emotive terms. It was not concerned with the restoration properties of natural environments, but with the purposive and imperative nature of natural componentry. If objects were rational and necessary and not excessive or flamboyant, then for Patricia they had purpose and their presence made sense. Alternatively, if they were not functional then they were not useful, nor necessary. 'That yellow thing that leads into the museum, is rather silly. Purely decorative. Not functional' (diary, August 2016), is how she described a tall walkway awning;

> this stupid thing…it doesn't work…it's just decorative it doesn't keep the rain off at all…if the rain's coming straight down it's ok but rain never comes straight down…and it's got this matching bus shelter which is just as stupid because it doesn't keep the rain out, it's got big gaps, at least there's a seat there. (interview, August 2016).

Practicality, purpose, usefulness and the easy recognition of these traits in built form are paramount to Patricia's daily activities; the lack of such attributes has only nuisance value. These traits are the lessons of natural form. In nature, excess is unwarranted and quickly rationalised; flamboyance such as the frilled neck of a lizard or the saturation of pink blossom on a cherry tree have purpose. Patricia did not describe or make any statements about a need for a more natural environment, only a need for the built environment to provide practical support to her life. It needs to emulate natural order—provide only rational and understandable construction and allow for easy navigation via logical and uninterrupted pathways so that she can readily understand its purpose. Being able to take the logical next step without having to hesitate, reassess and reorient to actively and consciously translate meaning is the honesty she requires of the urban environment

(Kaplan, Stephen & Kaplan, Rachel 1982). Patricia often commented on the way urban constructions forced her to hesitate and reassess. The extra effort required translating environmental information caused interruption to her movements, her progress and resulted in frequent frustration.

> Oh the stupid intersection, I can't think how it works now but I was here and I wanted to get to here and there's no lights…the pedestrian lights are on the other side of the intersection…I had to cross over, it's all turned out to be about traffic…there's a bus stop over there which is why I had to cross the road to catch the bus there…there's a slope on the road so that if you're crossing and there's a car here, like there was, you can't see what's coming (interview, August 2016)

> there's a school crossing a lot further down the road but the supermarket's here and the post office is there and the bus stop there, that's where people want to cross…it's busy but there's no button thing in the middle, so if you happen to be really slow and you only get to the middle you get marooned

Patricia's access to the urban environment is via buses and on foot. A public transport system therefore that does not streamline the connection between the transport itself and the users of the system is, in Patricia's words, 'stupid.' Built environment disconnection triggers physiological disconnection, requiring conscious and deliberate reassessment and translation work. This effort can be mentally exhausting. When processing activity shifts from the subconscious to the conscious, extra neural work is required. The ability to diminish these neurological activities and return them to the position of routine translations and insignificant interruptions to navigation processes is critical to resilience and environmental comfort. Patricia provides her

solution to this type of exhaustion, explaining that if the places she navigates are familiar and the challenges of navigation are routine, the effects of constant processing are tolerable. The tolerance however is based in the beneficial effects of routine and familiarity, not because her cognitive work is diminished.

> I suppose because I'm used to it, I mean when you come into a place you're not familiar with you notice problems, when you're used to a place you just take it. (Patricia, interview, August 2016).

Andrew not only concurs with Sullivan's idea of emulating the natural order of things, whereby 'life seeks and takes on its forms in an accord perfectly responsive to its needs', but he consistently holds a literal position on the notion that 'life is recognizable in its expression', often expressing built form in terms of human quality (Sullivan 1896).

> Franklin is a nice little village … it's just sort of nice and friendly, it's kinda hard when a place like that is built on a river and just about everything looks out on the river, it's hard to imagine a lot of negativity and stuff. (Andrew, interview, January 2016)

Andrew's perspective is common. Urban environments are consistently depicted as unfriendly, cold, disengaging and impersonal compared to more natural spaces, which are typically exemplified as providing comfort, neurological connectivity and personal nourishment. Andrew's language installed specific human traits into the inanimate objects of built form and he often transferred expectations and emotions gained from the experience of one place to others of similar componentry—for example, his one bad Woolworth's experience now prohibits him from entering any Woolworth's

stores, and the dimly lit, closed-down, cage-like, and less staffed Centrelink office warns him to stay away from there and other dimly lit places. Environments speak to him, but why and how, and is there an increased occurrence of this for people on the autism spectrum? Can built form actually display or emanate traits that are fundamentally human and if so where do they come from? If humanity can be built in, can it be installed into to the form itself, and if not, what else is required? Can a building, a group of buildings, or the arrangement of structures, actually be the manifestation of a person's head, heart or soul, and if so who can interpret the manifestations and how can the constructor be sure their structures are interpreted accurately?

Grace's built environment world-space is heavily endowed with humanity. She derives meaning from not only her experiences of place but also from her experiential perspectives, projecting human feeling into inanimate objects through a very sensitive lens.

> the thing I'm concerned about is that they're a bit too outside the community…so these shops in particular, these chain of shops in particular, they look a bit cast out … I just find it a bit disheartening because the view's back[wards] in some of the shops instead of looking inwards (interview, April 2016)

Looking inwards for Grace means all shop entrances facing the same direction, as a unified welcome to their customers. Looking backwards means the shops are turning their backs; their entrances are elsewhere. For Grace this means, 'they don't seem to belong' (interview, April 2016). Grace also described the city as having a heart (diary, April 2016). Her initial reasoning was one of practicality. The heart is a nexus, the point from where she finds easy access to the places she likes to visit. Grace's city's heart is literally the

central nodal point of her public transport-based life, which provides her access to places of interest and activity within acceptable walking distances.

> The Post Office building in Elizabeth Street to me is the heart of Hobart itself, from the town's wharf, the Theatre Royal, the TMAG, to the small hidden shop alleyways around the Cat and the Fiddle Arcade. Every Monday morning and early afternoon, this is where I catch buses from Rosny to Kingston. (diary, April 2016)

Moreover, while she initially reasoned the city heart to be a geographically central and convenient location, Grace later described a more experiential and emotional reason for her feelings. The post office had acquired the status of city heart not only because of its functionality but also because of her experiences there.

> Cause that's where, I remember when I was a kid, when my sister had to have several eye operations at the hospital I'd often go with dad, we'd take a bus from Kingston to there and that to me, it symbolised everything, from the hospital itself, to the theatre to the Hobart wharf. (interview, April 2016)

This experiential meaning is a significant part of Grace's score of experience. As discussed in chapter 3, section 3.2 spaces become places because of the meanings bound into them (Malpas 1999; Robinson & Pallasmaa 2015). This location 'symbolised everything' because Grace has connection there and, while the practical heart might shift because of changes to bus service infrastructure, the emotional heart would always be fixed to the place. 'What would you think if they changed the bus location, so suddenly they decided,

okay, the buses are not going to end there. Would you still consider it the heart?' I asked. 'Well yeah, I would,' Grace responded (interview, April 2016).

Finding connection to an urban place and linking it to another place of connection, then to another and so on, begins to build a person's network of spatial, social and sensorial connectedness. As Grace described, she frequents a network of favoured places, which now hold personalised experiential meaning. The built form componentry of those places is consistent, reliable and predictable. Grace knows what to expect of it and how to access it—it has legibility—and she can trust (generally) that those characteristics will not change. Human componentry however, does not provide the same surety. People are unpredictable, unreliable, and inconsistent and, for that reason, cognitively as well as socially, they cannot be trusted. When the surety of built form outweighs the unreliability of people, urban spaces become accessible to a broader spectrum of people.

This more objective and peripheral, less socially immersive, approach is what benefits Patricia's daily activities. By maintaining distance from the social environment and relying primarily on the fixed form of shared urban spaces she can also maintain a confidence of action. This surety is the 'grip' that Baumers and Heylighen (2010, p. 3) describe as important for people with autism.

> Living in an incomprehensible world, a lot of auti-biographers push forward the physical space as a source of certainty. Physical space, presented as a fixed and self-evident feature of the environment, gives a sense of grip the authors are looking for. The physical characteristics of space, which are directly perceivable, seem to inspire more confidence than human beings.

For Rob, this possibility seems appropriate. He stated his nervousness around large groups of people; 'when it gets to 30-40 I just can't really handle that because it's very unpredictable what people do, so that's what kinda disturbs me, when I see people doing things and I don't know what's going to happen' (interview February 2016). It also contributes to Andrew's anxieties about the Centrelink office which, when physically changed, became a significant deterrent because he could no longer trust the environment. If people followed the rules of shared urban spaces however, as discussed in section 7.2, their unreliability and unpredictability would be kept in check. 'Sort of goes back to the smokers' thing I guess', said Stuart, 'there are these rules in place but people don't always follow them' (interview, August 2016).

Thus built form can provide a consistency, reliability, predictability, and surety that people, most often, cannot. The more familiar a person, the more reliable, but strangers offer little assurance and therefore cannot be easily trusted. Trust, Jacobs (1961, p. 56) states, 'is formed over time from many, many little public contacts'. If the built environment is a trustworthy partner in the urban space dynamic, then there is greater space available for focus on socio-cultural mechanisms. Making meaningful connection to the urban environment requires forming connections through all avenues of psychological and physiological apparatus—spatial, social and sensorial—to ultimately secure the desired level of personal connectedness. The absence or weakness of one mode alters the overall strength of connection and causes imbalance but equally, confidence secured in one area can provide an invaluable foundation for the construction of the others.

PART 4

DISCUSSION
CONCLUSION

& IMPLICATIONS for FUTURE RESEARCH

chapter 8

Making space for autism

There isn't an answer; there is just better understanding,
broader consideration and an infusion of the
consequences of those two things.

8.1. In summary

This work is intended to uncover the operative environmental characteristics that surface feelings of social inclusion, exclusion, and isolation and to add to ongoing research and discourse that addresses the notions of *equal, normal,* and *universal* as applied to the built environment. This work questions experience in the context of the theory, policy, and practice of urban design and its socio-political responsibility to provision the rights of all people with access to, and occupation of, public space. The intent of this thesis is to explore the experience of autism in public urban places and to understand how those experiences impact everyday geographies.

To explore built environment experience I engaged with five people with autism who elected to participate in urban fieldwork in various ways. Two participants chose to record their daily activities by means of a diary, photographs, GPS tracking, and interview. Another elected not to use a GPS device and two people chose only to discuss their experiences with me in semi-structured interviews. The representations conveyed in this work provide empirical evidence that is used to question the epistemological foundations of contemporary urban design. In this chapter, I summarise participant experiences and examine whether they evince support for, or challenges to, the foundations and philosophies that underpin approaches to contemporary urban design.

In this study I have introduced the concept of a *Golden Record for Autism* as metaphor for epistemological shift. It is a concept drawn out of a discussion with one participant who eloquently described his understanding of my research objectives. Seeking a *Golden Record for Autism* is my metaphorical research objective, that is, to contribute to a common language of understanding that can be used to inform more holistic, more accessible and

equitable urban environments. I also introduce the notion of a *score of experience* as a way to describe a person's experience of urban spaces and their feelings of connection to environment. Like the score of a film, the score of experience fills the gaps between buildings and the spaces between people and determines the degree of connection a person feels with their environment. It is the *score of experience* provided by five people with autism that makes contribution to this Golden Record for Autism.

Section 8.2 *Autism space, place and environment*, discusses the participant experiences described in previous chapters— their encounters with ableism and their feelings of connection.

Section 8.3 *Discussion of limitations,* outlines the limitations of this research.

Section 8.4 *Conclusion - Making Space for autism,* discusses the evidence and implications of this research. *Making space for autism* is divided into three sections:

> *8.4.1. New lenses: making space for autistic voices,* has focus on research, highlighting the need for increased participation and contribution from autistic voices;
>
> *8.4.2. New language: making space for change,* has focus on shaping the built environment, describing the space that is needed to expand and inform built environment policy and guidance;
>
> *8.4.3. New form: making greater space for diversity,* has focus on built environment public space, positing what better city form might look like, and outlining what is included on this *Golden Record for Autism*.

Section 8.5, proposes *Recommendations for further research.*

8.2. Autism space, place and environment

Autism self-advocate Jim Sinclair (1993) contends that the neurotypical world has no place for people with autism. He suggests the experience of autism to be instinctively unfamiliar to typical experience. This factor suggests a fundamental disconnection between people with and without autism and, because neurotypical people predominantly shape the built environment, it also implies there is disconnect between people with autism and built form. Sinclair, however, does not view this standing as hopeless. With an epistemological shift, he proposes, connections can be made. Making those connections requires that people stop trying to remedy autism and instead, accept autism as a different way of being in the world.

Sinclair, together with Grandin, Hamraie, Yergeau, and many other self-advocates, encourage shift in understandings and in culture so that the idea of normal can be re-established. This critical shift has to address the deficit model of autism. It must confront the entrenched practice of 'othering' and the negative binaries used to diagnose, to rank, and to separate people. It must interrogate, consult, and re-frame understandings so that approaches and practices used to shape urban places are foundationally, and authentically, universally devised. Once embedded, there will be more influential space available for experiential voices and by suffusion of understandings, those actions will provision an improved place in the world for people with autism.

As discussed in chapter 3, it is intrinsically human, through the very act of experiencing space, to continually adjust in order to secure a place of personal world-space comfort. Environments, experienced through

physiological and neurological involvement with both tangible and intangible componentry, influence and often determine who is allowed access, their level of comfort, and their depth of engagement (Boys 2014; Imrie 1996, 2004a, 2012; Kinnaer, Baumers & Heylighen 2016; Mostafa 2013; Ryan 2005; Wiesel 2009). The premise of this thesis is that people with autism have to work harder—use 'more cognitive and emotional labour'—to make those adjustments, often to the point of exhaustion and often to the point of complete surrender. Removing or diminishing—even if only for a moment—a protective shield that has been carefully and likely painfully assembled into adulthood is for some people not a negotiable possibility. The fieldwork component of this research, therefore, was approached with a cautionary lens by asking people to become co-researchers, enabling them to tailor methods of participation, and by remaining flexible throughout the process. The five people with autism who shared their stories described varied experiences of autism and varied degrees and modes of engagement in and with shared urban spaces. They are individuals whose experience of autism falls in very different places on the spectrum. As discussed throughout this thesis there is no homogenous autism group and the research intent was to contribute to discourse that challenges stereotypes by gaining individual perspectives on experience (Baumers, S. & Heylighen, A. 2010; Baumers & Heylighen 2015; Davidson 2007).

In the context of people and their access to, and inclusion in, shared urban spaces, ableism works through the understandings and positioning of the idea of *difference* and the concept of *normal*. Sinclair (1993) describes this as recognition of a 'different way of being', Gray (2001) recommends a 'narrative reconstruction' to shift autism away from an illness narrative, Hansen and Philo (2007) call for a shift from thinking 'about' disability, to thinking 'with' disability, Boys (2014) suggests 'starting from disability' so it can be reframed to recognise diversity, Imrie (2004a) appeals for a decorporealization of the

codes and practices that shape the built environment, and Yergeau (2010) argues that the spectrum model of autism must be dismantled to remove the 'us/them reality' that it perpetuates. The shared core principle of the *difference* and *normal* argument is the need for fundamental recognition of human diversity. The hold of ableism in approaches to the shaping of shared urban places evidences the epistemological shift (the *Golden Record for Autism*) that is needed to improve access and inclusion for people with autism.

My investigation of ableism was searched from two perspectives: (1) approaches to the design of the built environment—chapters 1, 2 and 3—and, (2) the perspective of experience—chapters 4, 5, 6 and 7. With focus on autism, an analysis of each person's story evidences ableism playing a part in each of their lives in different ways. Significantly, however, although there was commentary about changes needed to some of the componentry of the built environment, the overriding perspective from participants was that any adjustments needed for access and inclusion into shared urban spaces are their own responsibility. The effects of ableism, therefore, are well entrenched into the perspectives of five people who are more likely (than most other people) to be subject to it.

- Andrew's non-definitive diagnosis of autism and/or Asperger's creates confusion in his life. He is unable to reconcile his own perception of his differences—those that manifest in his relationships with people and with the environment—with the perceptions of others. This uncertainty undermines his confidence, causes anxiety, and is actively closing down his access to shared spaces.

- Grace describes herself as 'pretty happy most of the time.' She did not explain or convey any feelings of discrimination for the differences

that she identified. What she did describe, however, was the targeted conditioning trainings she undertook as a child that now enable her improved access to shared places and participation in some 'normal' activities. Grace carries earplugs with her at all times so that she can more confidently access and occupy shared urban spaces.

– Patricia's perspective considers purpose and functionality to be primary in the practices of shaping the built environment and it supposes her views to be consistent with those of others. By maintaining a peripheral position in shared urban places she is able to deflect direct personal experiences of ableism. Paradoxically, it is ableism—the lack of understanding of how Patricia likes and needs to be included—that places her into that peripheral position.

– Ableism keeps Rob mostly at home. His sensory, spatial, and social challenges are ill considered by the shapers of urban places and, as a consequence, he finds little comfort outside of his home environment. Rob despairs about wanting to be social, gaining a 'normal' job, and having the freedom to leave his house without fear of anxiety and sensory overload.

– Stuart tailored his career to freelancing because he felt there were no other choices or options for him, and he tailors his time spent in shared places to minimise experiences of sensory overload. Occasionally, when the social imperative prevails, he subjects himself to the possibility of 'normal' exposure, willing to risk the potential for a negative physiological reaction. Stuart's answer to ableism is to better provision people with autism, to augment their realities so they can more easily understand the built environment.

I have described neurotypical understandings of connectedness to environment as an experience with three connection characteristics that operate through psychological and physiological avenues. The triad of connections discussed in section 3.6—spatial, social, and sensorial—work together, and if they are all successfully operational then—for neurotypical people—connectedness can be maximised. Connection to environment operates on an innate subconscious level through neurological and physiological interactions. Direct congruity of interactions between person and environment, plus memory generated from previous experiences, provides for greater connectedness. The three connection characteristics support each other and can be experienced on different levels such that the strengths and balance of different connection types makes for different connectedness experiences. I propose that because the built environment is constructed from neurotypical understandings of connection it does not enable people with autism to experience fully balanced and maximised connectedness. Experiences of autism mean that there will most likely be one or more connection characteristics that cannot be fully realised, or possibly, not established at all.

In consideration of the experiences shared with me about access and occupation of shared urban places, I submit that each of the five participants experience an imbalance in their general positions of connectedness. Andrew, for example, noted major challenges to his social and spatial connections, but described only minor issues that would affect sensory connection. Grace has primarily sensory challenges and as a response she tailors her social and spatial connections. Patricia appears to operate with a uniform level of comfort in all three areas but does so from an overall position that is removed. Rob experiences significant challenges in all three areas and has difficulty establishing connection of any type. Stuart operates

with a relatively high level of comfort in all three areas but can, on occasion, experience challenges to all three at the same time.

These generalisations are perhaps an over-simplification of the experience of connectedness and I do this thinking about one starting point for new urban design epistemologies. I suggest that gaining such understandings of the mechanics of spatial, social, and sensorial connection, if applied to urban design approaches, will enrich outcomes and improve opportunity for maximum connectedness to the built environment for people with autism.

8.3. Limitations

Gaining insights of experience from many autism voices will not only build a broader base of knowledge but will also assist with its resonance. Because of the extensive group that make up urban shapers, and the extensive process that is urban design, it is necessary that voices are loud and multiple. This research includes only five voices—they are adults, who self-identify with having Asperger's, they are from one socio-cultural base and live in very small urban centres even by Australian measures. There is limitation, therefore, to the breadth of experience that this group can provide.

Adults with Asperger's were nominated as the participant group for this research because (it was supposed) they (as opposed to children with their necessary caregivers) would be able to independently articulate their choices about built environment interaction and exposure. Recognising those choices, however, is reliant upon being able to reflect on and recognise decisions, most of which were subconscious and made progressively over the course of a person's life. A challenge to this research, therefore, was that as adults, these five people may in fact not have been able to, nor wanted to, identify and articulate specifics of environmental interaction that might have

contributed to their lifestyles because, (1) they had actually been very successful in honing their world-spaces and these specifics may be now deeply suppressed, (2) my interrogation might have provoked discomforts, and (3) they are now resigned to and accepting of their loci—they may not feel different.

Having only adult perspectives on the experience of autism in shared urban places limits contribution. Watson (2006, pp. 124 - 125) asserts, 'Because of increased fears for child safety, public spaces have become less for children and more for adults'. Ryan (2005; 2008; 2010), Tauke (2015), Whitehurst (2007) also contribute to discourse about the dearth of understanding, design consideration, and research contribution from and about children in urban places. The lack of perspective from youthful voices is limiting and risks further disenfranchisement of children though an urban design process that is heavily biased toward adult life. For this research, perspectives from children would have been invaluable. Due to ethical considerations, however, when working with children and with people deemed to have a cognitive impairment, it is necessary that a regulated and psychologically structured and considered methodology be implemented. The experience, expertise and certification required to facilitate such interactions would mean that a qualified person—other than the parent or carer—might also need to be present at all times. For this novel, highly qualitative urban design-based research study, however, the rigor of a more scientific and structured approach was considered inappropriate and the indirect, likely influenced input received from children's representatives, considered inconsistent with the research objective.

In chapter 5, I describe the lengthy process of participant recruitment and questioned both the effectiveness of my communication and the extensiveness of the fieldwork proposed. These factors may have impacted

volunteering. If my words and description lacked clarity and the fieldwork appeared complicated then potential volunteers were possibly discouraged. Those who chose to participate, therefore—with the exception of Rob who was actively encouraged by an Autism Tasmania member—could be considered as more confident and outgoing than their peers. Again this limits the breadth of experiences conveyed to people who have a relatively high level of comfort in their world-space. This means, therefore, that the voices of many people who lack such comfort—important contributors—were not heard.

In general, the small number of varied voices that contributed to this research presents a limitation. From that perspective it can only make a small contribution to current discourse. Greater numbers of people with autism from varied positions on the autism spectrum, of all ages, from different cultural bases, and from larger urban centres, who experience different immersions and intensities of urban life, plus their families and extended support groups, are needed to provide a greater depth of understandings for non-autistic others.

8.4. Conclusion - making space for autism

While challenges to the concept and understandings of difference and interrogations of how individuals relate to the world continue to evolve and advance, conceptions are reliant upon holistic responses and these are still falling short of being truly supportive. Diversity can be more effectively built into urban places if conceptions of diversity itself are challenged, then advanced so that foundational epistemologies are broadened to include new, more reliable, and more holistic understandings. To make space for autism it is necessary to begin by asking the right questions of the people who have the answers.

To make space for autistic voices, a continued evolution of participatory research is necessary. People with autism need to be included and to have a more directive role in the process to challenge traditional power imbalances.

> This will not come easily and can only happen with considerable effort from relevant communities and stakeholders, as well as evaluation of the effectiveness of participatory methods. The opportunity is to create a burgeoning, merged community of research practice, including autistic and non-autistic people and other partners who work collaboratively to create facilitative environments and resolve important, relevant questions. (Fletcher-Watson *et al.* 2018)

8.4.1. New lenses – Making space for autistic voices

For the alien beings targeted by *The Golden Record*, there could be no certainty about methods and understandings that might enable communication and inaugurate connectedness, but for human beings it is our humanity that is enabling. The differences of experience described by the five people who participated in this study reveal atypical responses to the environment, they do not introduce scientifically alien properties that can never be interpreted nor understood. Sensorial feelings, cognitive processes and perception are not fundamentally alien. There exists differences in the way these processes operate but it is the operation of social constructs and their default to normalcy that determine alienism. Jim Sinclair (1993, pp. 2 - 4) spoke of alien children ‘stranded in an alien world’ but he qualified alienness as follows,

> The ways we relate are different. Push for the things your expectations tell you are normal, and you'll find frustration, disappointment, resentment, maybe even rage and hatred. Approach respectfully, without preconceptions, and with openness to learning new things, and you'll find a world you can never have imagined. Yes, that takes more work than relating to a non-autistic person. But it can be done—unless non-autistic people are far more limited than we are in their capacity to relate.

The process that springs from that basis falls then to a position of mutual respect and equitable foundation. It requires a willingness to abandon preconceptions and accept new perspectives. If properly researched, developed and integrated, any accommodation of difference will be of benefit to all.

Contemporary research into inclusive design practices recommends collaboration such that the designer and the user cooperate in the design process to provide quality outcomes; it is 'not simply a matter of convergence of different perspectives, but as a matter of cooperative integration' (Heylighen & Bianchin 2013, p. 119). It is about recognising that many people do not see themselves within the rudiments of design practices and changing the fundamentals of design approaches. Such collaborative practices, plus insight from self-advocates, are progressing understandings of the way in which people on the autism spectrum engage with the world and is further diversifying the definition of autistic difference (Baron-Cohen 2002; Baron-Cohen & Belmonte 2005; Dakin & Frith 2005; Fletcher-Watson *et al.* 2018; Samson *et al.* 2012). Even Grandin (2009a, p. 1439) corrected her own 1995 account, changing it from a belief that, 'everybody on the autism/Asperger spectrum was a visual thinker' to describing individuals as 'specialist thinkers', and noting, 'I have concluded that there are three types

of specialist thinking … (i) Photo-realistic visual thinkers—such as I … (ii) Pattern thinking—music and math mind … (iii) Word—fact thinkers'. While it is necessary as a starting point, and understandably advantageous for the purposes of research and assistance, to continue to group people into analogous identity categories, it is important to recognise that the Spectrum is replete with individuals who must be individually understood.

Although the stated intent of this research is to gain diversity of advice about experience, there is still danger in the potential for generating a singular conception of an autistic identity and, for the purposes of generating a conclusive research statement, in attempting to address particular issues to that stereotype. Identity is multiple and is 'related to the spaces that we inhabit at any particular time' (Bertilsdotter, Brownlow & O'Dell 2013, p. 369). Rob's 'comfortable level' of human contact for example, is no different to a neurotypical response. It is uniquely specific to his personal tolerances and specific to the space he inhabits at the time. The critical difference is that as long as he remains unsupported by his environments and feeling uncomfortable, anxious and isolated from human contact, Rob will consider himself to be different and, by means of the same constructions, the people around him will generally reinforce his position. Thus multiple spectral perspectives are needed to fight the tendency toward stereotyping and also to assist the 'neurotypical' population to realise that the spectrum is in fact inclusive of the entire human population, and that urban space comfort for everyone is dependent on relative time/space experiences.

Making space for autistic voices needs also to recognise that autistic people, like those described in this study, are themselves entrenched into the ableism paradigm. As discussed above there is common belief that the adjustment of difference lies with the person rather than with the system that determines what difference is. For example, Rob views his isolation as self-isolation. He

wants to leave his house more often, describes trying to push himself because he knows it is good for him to test his limitations, and blames himself for his inability to do so. Grace is happy in her world-space and readily adjusts to be in urban places, and Patricia's acceptance of her peripheral position also relieves others of having to make any adjustments because her acquiescence concedes her differences of experience to the norm. These actions are part of the paradigm that needs to be shifted, so there is disturbance necessary, and as Fletcher-Watson *et al.* (2018) state, it will not come easily.

The greater understanding that I now have of the varied and complex experiences of people leaves me with an equally great concern for the effective implementation of positive change. The change that is necessary to foster the provision of more inclusive environments requires a relentless hammering toward a fundamental shift in perspective. The experiences communicated here, and I suggest any collective of autism voices, do not provide a neat package of ideas waiting to be implemented. Nor do the experiences communicated allow neurotypical urban shapers to gain understandings of unique experiences by means of assuming an autism lens. What is possible, however, is that urban shapers can be provided with a form of assistive multi-focal lenses. Like the glasses of enhanced vision alluded to by Stuart, we can be provided with a supplemental lens to augment our perspectives, lenses that distort our neurotypical vision so that an alternative reality can be accessed and better understood. The change required is foundational and all we need to do to commence the process of change is to ask the people with the correct vision.

There is action is this space. Contemporarily, disability and autistic advocates are engaging directly with the problems of input and exposure. For example, created in 2014 by Alice Wong, the Disability Visibility Project (DVP) is an 'online community dedicated to creating, sharing and amplifying disability

media and culture' (Wong, 2014). The DVP not only works to give voice but to maximise reach by encouraging disabled narrative and activism, through publishing, organising, supporting, partnering, and consulting. Another similarly dynamic collaborative based at Vanderbilt University Tennessee, is the Critical Design Lab directed by Aimi Hamraie. The Lab's bio describes it as a 'multi-disciplinary and multi-institution collaborative drawing on the methods of critical and interrogative design, intersectional feminist design theory, and crip technoscience to address thorny questions about disability' (Hamraie 2020). One of the outputs of the Lab is a participatory access-mapping tool that operates as a 'map-a-thon' process. The purpose of the Mapping Access approach is to 'build commitment toward broad accessibility … to craft alternative standards for meaningful access' (Hamraie 2020). Mapping Access invites users—as 'experts in the design process'—to generate their own environmental surveys, to collect data, and, as part of the process, they are encouraged to create new mapping methods. Mapping Access is a process that is—very purposefully—not static. Rather, by asking users to layer additional and unique information into their surveys, the mapping tool constantly searches for, calibrates and describes lived experience. It allows for the multiple ways of being in the world to inform the design practice.

With such all-inclusive perspectives as a starting point, that is, with recognition that it is degrees of humanness that are being addressed, it should not be a far stretch to broaden the spectrum of understandings. With such an approach the outcomes will be more holistic, more resilient to the pressures of oversimplification, and more easily adopted by the broader population. *Different* needs to become understood to be the new *normal*.

8.4.2. New language – Making space for change

Gaining multiple perspectives is only one part of the process toward making space for autism. Working collaboratively toward the application and implementation of perspectives to ensure relevance and maximise meaningful outcomes is critical to the process (Fletcher-Watson *et al.* 2018). Urban shapers need to gain understandings, recognise shortcomings, and buy into the process of incorporating and implementing alternative, unfamiliar perspectives. The shift is epistemological. The *scores of experience* provided by multiple autism voices, collaboratively gathered, are the mechanism for change. The provision of equitable access does not end with the provision of an inventory of accommodating structures and services. Universal and inclusive design philosophies and practices must continue to evolve with new language and to infiltrate alternative *scores of experience* into entire socio-cultural-political-built networks to a point where all-inclusive practice is the norm. Expanding conversations, placing greater emphasis on collaborative holistic thinking, and consulting a broader spectrum of user perspectives will assist in challenging parameters of diversity and dismantling the ableist paradigm.

In the Introduction, I expressed a primary socio-cultural objective: to reach Jim Sinclair's desired state of understanding that acknowledges difference as part of the spectrum of normal. Once this basis is established, focus can shift from seeking cures for a disorder to seeking improved means to accommodate difference. There is risk, however, in the execution of this acknowledgement. Normalising difference can also shift focus away from the specific needs of the perceived *non-normate* and sabotage the imperative for change to neurotypical perspectives. The recognition of difference as normal does not absolve people of the responsibility for identifying the entrenched ableism that exists in our socio-cultural and built environments, and in the

approaches to the shaping of those environments. It is critical that neurotypical perspectives realise that the spectrum of normal includes diversity and that because urban environments have been devised with only the normate, or a counter to the normate, in mind, ableism exists. Fundamental epistemological change is necessary not only to entrench collaborative participatory practices, but also to re-vision the practices themselves.

Medicalised approaches that contribute to *othering* are being progressively challenged and it is necessary that expanded definitions and understandings are shaped and circulated, to gain hold in the domain of urban shapers. Given the 'mongrel' discipline of urban design that Carmona (2014a) and Dovey (2016) describe, which draws from sociology, psychology, health and political sciences, as well as the traditional space-based and creative disciplines, and which Dovey defines as an 'between condition', it does not seem inconceivable that this shift is possible. What is problematic is the pace of change and the tendency for simplistic and synthesised versions of new understandings and processes to take hold and become fixed as people search for new binaries of right/wrong, correct/incorrect, or appropriate/inappropriate. Urban design frameworks need to be open, curious, dynamic, and importantly, they need to be humble.

Urban design as a process is multifaceted, multi-disciplined, and complex. Urban designers, as agents for that process, cannot possibly operate in isolation. The continued pursuit of collaborative frameworks built on mutually respectful associations is essential. Dovey (2016, p. 1) describes 'assemblage thinking' as one framework that has the capacity to address the multifarious nature of urban design.

> it provides particular capacities for rethinking the city in ways that prioritize connections between things over things-in-themselves: differences over identities, co-functioning over functions, complex intensities over simple densities. Assemblage thinking involves understanding the morphogenetic processes through which the city emerges. It is based on a philosophy of becoming rather than of fixed forms and identities.

It is this in-between philosophical thinking that can pursue and inform change to policy and guidance for urban shapers. Space needs to be both given, and taken, to allow change to occur. If urban shapers focus on the in-between, the connections, the space, the missing, and consider it operationally as a series of small steps, of layering information, 'minor adaptations and tactics in contrast to the major strategies of master planning … informal network connectivity in contrast to hierarchical control', then there is greater opportunity for change (Dovey 2016, p. 264). If urban shapers acknowledge and embrace the multi-disciplinary and multi-scalar nature of the process of urban shaping and recognise it as a 'synergy of density, mix, and access, [i]t opens up an understanding of the way in which a city embodies capacities for change – gearing the study of the actual city to its possible futures' (Dovey, Rao & Pafka 2018, pp. 2-3).

Part of the *making space for change* process is understanding that there are different ways of being and different ways to be social. Shared urban spaces, shaped to house the complexity of daily interactions, activities and encounters of people, need to provision those differences. New language for the *Golden Record for Autism* requires making space to acknowledge that difference is a normal part of the human condition, that difference and normal are socio-cultural and political constructs, that socio-cultural and

political constructs can be shifted, and that the responsibility for being different does not rest with the person whom those constructs label as different. New language for urban design requires opening up space to allow change to happen. If, as Yergeau (2018) suggests, being autistic is 'to live and to lie in a between space' and, if urban shapers give focus to the 'connections between things over things in themselves' (Dovey 2016, p. 1), then there is synergy and there will be greater opportunity for alignment.

8.4.3. New form - Making greater space for diversity

> A good city street neighborhood achieves a marvel of balance between its people's determination to have essential privacy and their simultaneous wishes for differing degrees of contact, enjoyment or help from the people around. This balance is largely made up of small, sensitively managed details, practiced and accepted so casually that they are normally taken for granted. (Jacobs 1961, p. 59)

The shared urban spaces of the built environment are places for all. Lefebvrian philosophical discourse suggests that access into and occupation of those spaces are the right of every citizen. Top down, political tenets, policies, and guidance disseminated through the United Nations (2006), ADA (*Americans With Disabilities Act 1990* (USA)), Disability Discrimination Act (1992), Universal Design (The Center for Universal Design 2008) and a multitude of inclusive design principles also describe equitable rights of access and inclusion as fundamental to being urban. Seminal urban theorists such as Jacobs (1961), Lynch (1960, 1981), Gehl (Gehl Architects 2016; 2007; 1987), and Whyte (1980), describe the existence of difference and the encounter with difference to be essential ingredients of city life and part of a healthy ecosystem that sustains urban inhabitants. It follows, therefore, that

shared urban spaces should provision equitable access and that inclusion should be a primary agenda for urban shapers. In theory and in practice the provisions and agendas of equitable access and inclusion do exist—as directed by the top down administrations noted above—and they continue to evolve and continue to improve their reach. However, many people with autism still find it difficult to access and to occupy urban spaces and as a result feel excluded and experience isolation. This research is an exploration of those experiences, intended to uncover the operative environmental characteristics that influence feelings of connectedness in shared urban spaces, and to contribute to the urban design evolution toward more equitable access pursued by others (Baumers, S. & Heylighen, A. 2010; Davidson 2010; Imrie 1997, 2001; Kinnaer, Baumers & Heylighen 2016; Madriaga 2010; Mostafa 2013; Ryan 2005; Ryan & Räisänen 2008; Wiesel 2009; Wiesel, Bigby & Carling-Jenkins 2013).

Lynch's (1981) proposition for *good city form* and Jacobs' (1961) beckon to urban shapers, call for holistic consideration of the needs of people, for the safeguarding and promotion of human values, fostering of wellbeing, instatement of flexibility, recognition of diversity and maximisation of connection. Their concerns advocate for the health and growth of cities and the quality of life of urban inhabitants. These values and approaches are still fundamentally what urban shapers pursue. Lefebvre (1991; Lefebvre, Kofman & Lebas 1996), Whyte (1980), Gehl (2011), Frumkin (2003), Carmona (2010), Inam (2011), and Dovey (2007, 2010, 2016) also speak this language of people first. However, I propose that the epistemological underpinnings that guide the pursuit of those principles require adjustment. New and better city form is about *making greater space for diversity*. As stated in the Introduction, although Lynch includes the characteristics of sense, perception, and mental capability into the determining dimensions of his theory, I position Lynch's

approach to diversity—and in general those of urban theorists following—as being wholly subject to neurotypical perspective.

Improved understandings in the relationship between people and their environments can provide fundamental guidance for varied design responses. Creating better diversity in place typologies must be a tenet of a new design approach. This investigation of possible contributions to a *Golden Record for Autism* considers the more holistic scores of individual experience and suggests that there are possible ways to make greater space for diversity. Full immersion into a shared urban space is only one option for inclusion. I propose that connectedness can be achieved in ways that are less demanding of physiological and neurological function. Firstly, the connections that comprise a person's feeling of connectedness must be understood. Neurotypical conceptions of what constitutes connectedness have to be unpacked, reinformed, reimagined, tested, and disseminated and this can be effectively done via the assemblage method discussed above. Focus must re-prioritised and taken away from objects themselves and given to the synergies operating between. And, authority must be given to the varied users of public spaces to construct new understandings of unrealised connective tissue.

Spaces that provision spatial, social, and sensorial connection in differing degrees and with different exposures can offer feelings of connectedness. With improved understanding that there exists a multiplicity of connection needs and preferences, and by actively engaging with users, urban shapers can re-think space typologies. I suggest the provision of urban spaces within spaces, or, built form adjuvant spaces offering; (1) spaces for cognitive rest, (2) spaces for retreat, (3) spaces that allow varied experiences within shared places, and (4) spaces that allow varied engagement with urban life. This

diversity of spaces can provide opportunity for greater options of shared urban space immersion for people with autism.

Considering (1) *spaces for cognitive rest*, the presumption that all people can tolerate similar levels of sensorial activity should be replaced with the knowledge that varied tolerances are the norm. The neurotypical expectation that a person's presence in an urban space means they are at all times in wont of—generally high levels of—social, sensorial, or built form interaction, must be corrected. Spaces that offer differing levels of physiological engagement will provide improved urban options for a greater diversity of people. If, for example Rob knew that he could leave his house, step out of his car and be assured of locating a space with subdued sound, low smell, and minimal or no people intensity when he required it, he might feel less anxious about leaving.

Considering (2) *spaces for retreat*, which may be a version of (1) or, they may be something spatially located that offers safety through distance, or enclosure, or openness. Determining what retreat means for different people will offer new forms of spatial structure to the urban environment. If Grace were to retreat it might be to the quiet of a museum-like space, Stuart might prefer a room of digital immersion, and for Andrew it might be a parklike space with the sounds, smells, and views of bushland. It is also possible that a singular spatial and structural apparatus, one that provides user options at the tap of a fingertip—an adaptive augmented or immersive digital reality for example—could provision all three retreats.

Considering (3) *spaces that allow varied experiences within shared places* could be argued as a being nothing new in the context of contemporary approaches to urban design. The philosophy that urban space is available to all people, that it should place the needs of people above economic and political

activity, and that it should accommodate a varied population, are not contested ideas. The alteration, for which I lobby, however, is that greater understanding of the 'varied experiences' of people is critical. An epistemological shift in the socio-cultural and political production of urban places is necessary so that varied experiences can be had without the derogation of individuality. A disabling built environment and an enabled neurotypical population are a formidable barrier to diversity, but shared spaces that offer a congruity of experiences with place types will dismantle both physical and social barriers. If Andrew, Grace, Patricia, Rob, and Stuart can easily navigate through and within places that offer differing levels of physical or social engagement, cognitive rest, or places for retreat, then their individual comfort levels will be better accommodated. For urban shapers, especially designers, this prospect should be an exciting challenge.

Considering (4) *spaces that allow varied engagement with urban life*; it is the informed understanding of the multiple users of urban spaces and the assemblage of their connectedness requirements that will assist with the assembly of urban form. Exploring and addressing the multitude of ways to be social can counteract the throw-together of shared urban spaces. The ability to be present but to also choose the degree of immersion into, and interaction with, the activity of the place could provide greater opportunity for people who struggle in neurotypically-devised spaces. With the provision of varied space typologies the expectation of normative interaction can be removed or altered such that different space typologies will allow for different types of action and interaction. Like the invisible cloak of a fairy-tale, if a shared urban space offered opportunity for individually selected, safe, and spontaneous engagement, Patricia might expand her everyday geographies and the length of time she chooses to stay.

8.5 Recommendations for further research

Building from the autism and built environment research of Madriaga (2010), Baumers and Heylighen (2010; 2010; 2015), and Owen and McCann (2016), this research continues and confirms the value of and imperative for participation and collaboration from people with varied experience of environment. Madriaga's study of everyday geographies challenges the misrecognition of diversity within Asperger's diagnosis and surfaces the value of experiential participatory research as means to gain more in-depth and representative contributions. Baumers and Heylighen note the value of autobiographical account to 'raise the corner of the veil covering the autistic perspective on the built environment', and recommend further research of actual lived experience. Owen and McCann using photo-elicitation determined the built environment to be a 'substantial factor' affecting the experience of university students. These studies provide direction for progressive and meaningful research. Future research into, and studies of, experiences in shared urban spaces—especially those that offer alternative neurological perspective—need to pursue personal stories in a way that can capture embodied experience. Methodologies must continue to evolve to become more holistically inclusive and they must be flexible and reflexive in approach and in practice so they can accommodate, gain access to, and better understand, personal *scores of experience*.

To further participatory and collaborative autism-built environment research, I suggest two approaches; (1) begin with a group discussion of volunteers in a safe place of their choosing and from there work collaboratively to develop and design personalised methods to capture and express individual experiences, and (2) tap into the nebulous fourth dimension by using music as a conduit. Adding aural methods to visual as well as written and spoken, and augmenting reality as Stuart suggests, could

facilitate a more thorough comprehension of different experiences of space. Gaining diverse advice from diverse perspectives is the only way to develop a more translatable language of shared understandings to inscribe on the next cut of a *Golden Record for Autism* and, developing such a language is critical to the provision of more equitable urban space.

APPENDIX

FIELDWORK FORMS

SCHOOL OF ARCHITECTURE AND DESIGN

INVITATION

Do you have Autism or Asperger's

Do you live in a city or town in Tasmania?

Are you over 18?

- If you answered yes to these three questions can you please help us with our research

- We want to learn about how the design of public spaces in cities and towns affects the experiences of people with Autism and Asperger's

1

We would like you to use a GPS to map your daily routes through public spaces for seven days – we will loan you a GPS device and show you how to use it

2

We would like you to take photos of things that you see in the spaces – we will loan you a camera

3

We would like you to tell us about your experiences in the spaces. To do this you can use a voice recorder or a write in a notebook or just tell us. We will loan you a voice recorder and a notebook

If you want to find out more about this study please contact Cathryn Kerr and she will send you an information sheet

Email: cathryn.kerr@utas.edu.au

Information Sheet

You are invited to be in a research study being conducted by the University of Tasmania.

The study title is:

Mapping the experiences of public urban spaces for individuals with an Asperger's or Autism Spectrum Disorder.

Study background:

This study is being conducted by PhD candidate Cathryn Kerr as part of an urban design, higher degree research thesis through the School of Architecture and Design, under the supervision of:

- Dr. Ceridwen Owen,

  University of Tasmania, School of Architecture and Design

- Associate Professor Elaine Stratford

  University of Tasmania, Geography Discipline, School of Land and Food, Deputy Director - Institute for the Study of Social Change

What is the purpose of the study?

This study aims to explore how the design of public, urban spaces impacts on the experiences and behaviours of people with Asperger's and ASD.

The purpose of the study is to investigate how urban design influences social inclusion, exclusion and isolation for people with Asperger's and ASD.

Why have I been invited to participate?

You have been invited to participate because of your self-identification with, or diagnosis of, Asperger's Syndrome or High Functioning Autism, and because of your association with the Asperger's group.

You do not have to participate just because you have been given this information sheet. You can choose to do the research if you want to.

What will I be asked to do?

You will be asked to do the following two things:

1. **Fieldwork**: We will give you a GPS device that you can carry with you so you can record where you go when you leave your house each day for seven days. It can be turned on and off when you choose. We will also give you a digital camera to take photos and a diary to write notes about things you see and a digital voice recorder to record your comments if you wish to. (If you do not want to use a GPS you can still be in the study)
2. **Meeting**: We will meet for a discussion to talk about the GPS maps and photos so you can explain your experiences to the researchers. We would like to record the discussion (just your voice) so that we are able to remember everything that you tell us.

Are there any possible benefits from participation in this study?

- Your information will provide new and valuable insight to the wider community.
- It will help with more urban design and ASD research, and with discussion and activity in the design profession.

Are there any possible risks from participation in this study?

- There might be some things in this study that make you feel anxious or stressed.
- But you will be able to stop any activity or discussion if you choose.

What if I change my mind during or after the study?

- You can withdraw at any time during study and you do not have to provide any explanation for this.
- If you choose to withdraw after the study is finished it may not be possible to remove the information you have provided but your name will be removed and you will not be able to be identified.

How many people are in the study?

- There will be 15 to 20 people participating in the study.

How much of my time will the study take?

- The fieldwork part of the study goes for seven days. You will be able to choose seven days that suit you best.
- The discussion will take about half an hour, but it can be shorter or longer if it needs to be.

What will happen to the information I give you?

- We will gather everyone's information together so we can get an idea about how the design of public spaces in cities and towns affects the experiences of people with Asperger's and ASD.
- This information will be written up as a PhD thesis and submitted for examination.

- We might also publish this information in journal articles and present it at academic conferences.
- All of the information you give to us is private, we might use your sentences but we will not print your name. We will give you your sentences to check before we use them.
- If we want to use some of your photographs we will ask your permission first. You can choose which photos we can use or tell us that you do not want any of the photos to be used.
- We will present your GPS maps as diagrams so that the places you have been cannot be identified.

What will happen to my information when this study is over?

- All digital information (photographs, audio files, GPS maps and electronic word files) will be stored in a password-protected file on a secure server at the University of Tasmania.
- Only the members of the research team will have the password for the file.
- Photographs and audio recordings will be deleted as soon as they are saved into the file.
- Printed photographs and diary writings will be stored in a locked filing cabinet in Cathryn Kerr's office, in the Engineering Building, Sandy Bay campus.
- Your name will not be in the file; your information will be identified by a code number.
- It will be stored for a period of five years following the publication of the thesis.
- After five years all paper-based data will be shredded and electronic data will be permanently deleted from the UTAS server by a member of the IT staff.

If I have any questions about this study who can I contact?

- If you have any questions about any part of this study you can contact Cathryn Kerr.

  Email Cathryn Kerr at: cathryn.kerr@utas.edu.au phone: 04 ....

What if I have concerns or complaints about this study?

- The Tasmanian Social Sciences Human Research Ethics Committee has approved this study.
- If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on 03 6226 6254 or email human.ethics@utas.edu.au.
- Please give them this ethics reference number H0015145

I would like to participate, what should I do next?

➢ Send an email, or phone Cathryn Kerr and tell her you would like to participate.

- Email Cathryn Kerr at: cathryn.kerr@utas.edu.au
- Phone: 04 ....

SCHOOL OF ARCHITECTURE AND DESIGN

Participant Consent Form

I would like to take part in the study named:

'Mapping the experiences of public urban spaces for individuals with Asperger's'

I give my consent to participate and agree to the following:

1. I want to be in the research study.
2. I have read and understood the Information Sheet.
3. I have asked any questions that I wanted to and they have been answered.
4. Everything about the study has been explained to me.
5. I understand that I am asked to do the following things:

   a) Fieldwork:
   - For seven days I will use a GPS device to record my daily routes of travel.
   - I will not have to change my daily routine to do the fieldwork activity.
   - The researchers will lend me a GPS device as well as a digital camera, digital voice recorder, a diary and a USB memory stick to use for the fieldwork activity.
   - If there are times that I do not want the GPS on I can choose to turn it off.
   - I can use the digital camera to photographs.
   - I can take as many or as few photographs as I would like to each day.
   - I understand that I should try not to take photographs of people's faces.
   - If I choose to I can use the voice recorder to record my thoughts, or I can write them in the diary.

   b) A few weeks after the fieldwork I will go to a meeting to talk about my recordings:
   - At the meeting I will be able to add to, change or correct the information that was recorded.
   - I understand that this meeting will be recorded by a digital voice recorder unless I decide that I do not want it to be.

   c) I will be given a copy of the information that will be used by the researchers so that I can check it:
   - I will tell the researchers if anything needs to be changed or deleted.
   - I will have three weeks to do this.

6. I understand that the discussions with the researchers might cause me some anxiety or stress. If this happens I understand that I can tell Cathryn that I want to end the discussion or change it to a different time.
7. I agree that photographs I take can be used and published in the researcher's thesis or for a presentation at a conference.

8. On the lines below I can write a list of the photos that the researchers can use in the thesis or at a conference. I can tell the researchers that I do not want them to print any of my photos in the thesis.

_____

_____

_____

_____

9. I understand that all of my research information will be securely stored on a University of Tasmania server for five years. Written information will be stored in a locked filing cabinet in Cathryn Kerr's office.
10. The researchers might use my recordings and sentences in a report or during a presentation at a conference but will not say or print my name.
11. I can tell the researchers that I do not want to be in the research study anymore and they will delete all of the information I have given them. They cannot delete my information if the report has been written.

Things I would like the researcher's to know:

1. **During the study I do not want to:**

- _
- _
- _
- _
- _

2. **During the study I will need to:**

- _
- _
- _
- _
- _

Participant's name: _____

Participant's signature: _____

Date: _____

Statement by Investigator

☐ I have explained the project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have had the opportunity to contact me prior to consenting to participate in this project.

Investigator's name: _____

Investigator's signature: _____

Date: _____

SCHOOL OF ARCHITECTURE AND DESIGN

PARTICIPANT No.	STUDY TITLE **Mapping the experiences of public urban spaces for individuals with an Autism Spectrum Disorder**

Fieldwork Schedule

1	2. FIELDWORK							3	4
INTRODUCTORY MEETING	**DAY 1**	**DAY 2**	**DAY 3**	**DAY 4**	**DAY 5**	**DAY 6**	**DAY 7**	**RETURN EQUIPMENT**	**MEETING / DISCUSSION**

Note: These dates can be changed. Please contact the Cathryn Kerr if you want to change them.

Email: cathryn.kerr@utas.edu.au Phone: (03) 6226 2123

Equipment Information

1. GPS – Garmin eTrex 20x

Switch On – use the button on the side next to the word 'light'

Record – when the GPS is switched on it is recording. You can leave it on when you go in and out of buildings or in your car. When you go inside the GPS loses connection with the satellites so it does not record your movements.

Switch Off – use the button on the side next to the word 'light'

Change Battery – spare batteries supplied in the box. Lift and turn the silver ring on the back of the GPS and it will open the cover so the batteries can be replaced.

2. CAMERA – Nikon Coolpix L31 Digital

Switch On – press the small ON/OFF button on the top

Take photos – use the screen on the back to see what you are taking a photo off and press the large silver button on the top to take the photo

Zoom in and zoom out – rotate the silver ring around the large silver button to the 'W' to zoom out or the 'T' to zoom in

Switch Off - press the same small ON/OFF button on the top

Change batteries – if you need to change the batteries there are some provided in the camera case. The battery compartment is on the bottom of the camera.

3. VOICE RECORDER – Philips Digital Voice Tracer

Switch On – slide the 'Hold On/Off' switch on the side toward the bottom of the recorder for 2 seconds and let it go. You will hear a chiming sound when you let it go. This is to indicate that it is switched on.

Record – press the silver circle button with the red dot. A red dot will appear on the screen and a red light will sow on the top of the recorder. You are now recording. You can hold the recorder or sit it on a table next to you.

Stop recording – press the circle button with the triangle and square on it.

Note for you – you can start and stop recording as many times as you like.

Turn off – Turning off the recorder is the same as turning it on – slide the 'Hold On/Off' switch on the side toward the bottom of the recorder for 2 seconds and let it go. You will hear a chiming sound when you let it go. This is to indicate that it is switched off.

Note for you – the recorder will turn itself off if you stop talking for a long time or if you forget to turn it off. So, you will need to switch it back on when you want to use it again.

Note for you – there are spare batteries in the box if you need them.

4. **BLUE NOTEBOOK –** You can use the notebook to write or draw things about your experiences

5. USB MEMORY STICK – Blue SanDisk 8GB Cruzer Switch

On the memory stick are seven forms that you can write on when you plug it into your computer.

The first is a form for general comments about your experiences in the public environment.

Then there are seven 'Daily Fieldwork Notes' sheet forms, one for each day. You can use these to write on if you do not want to use the notebook or the digital voice recorder.

Return of equipment:

On your Fieldwork Schedule we agreed that the date for the return of equipment is:

Cathryn Kerr, will contact you to arrange for the collection of these items.

Fieldwork Information Sheet

Your participation is voluntary:

- Your participation in this study is voluntary.
- We will need your *Consent Form* by [insert date] if you wish to be involved in this study.
- Your decision about participation will not affect any other connections you may have with the university.

What if I change my mind during or after the study?

- You can withdraw at any time during study and you do not have to provide any explanation for this.
- If you chose to withdraw after the study is finished it may not be possible to remove the information you have provided but your name will be removed and you will not be able to be identified.

What will I be asked to do?

- Go to a meeting to talk about the following things:
  - The equipment that you will use for the fieldwork.
  - How to do the fieldwork.
  - When you can do the seven days of fieldwork.

At the meeting Cathryn will give you five things and explain how to use them.

1. **A GPS device**
2. **A digital camera**
3. **A digital voice recorder**
4. **A diary**
5. **A USB memory stick**

- The next step is for you to complete the fieldwork which includes the following things:
  - Use the GPS
    - Carry the GPS with you when you leave your house.
    - Turn the GPS on in the morning and off when you get home.
    - If there are times when you don't want the GPS to be on, you can turn it off and back on later.
  - Use the digital camera to take photographs of anything interesting in the public spaces.
  - Use the voice recorder to record comments or stories, or write them in the diary.

How long do I have to carry the GPS for?

- For seven days
- The seven days do not have to be in a row but you should not take longer than two weeks to do the fieldwork.
- At the meeting we will decide on the days for this.

Where should I go?

- You do not have to do any different or special activities on the seven days of the fieldwork.
- You can do your normal daily things.
- You do not have to go to new or different places.
- It is OK if the places you go are places that you go to every day or if they are places you have not been before.
- It is OK if you do the same thing every day.
- It is OK if you travel by car, bus or walk. We would like the GPS to record information about all of these activities.

What should I take photographs of?

- You can take photographs of:
  - Things that are built as part of the public spaces.
  - Anything that you find significant, interesting, annoying, pleasant or funny.
  - Anything at all that gets your attention.
  - It could be a building or part of a building.
  - It could be pathways, seats, walls, steps, gardens, artwork or lights.
  - Try not to photograph is people's faces, but it does not matter if you do accidentally photograph faces because we can edit or delete the photos later.

What do I do after I have finished the fieldwork?

- Cathryn will contact you to collect the five items (GPS device, camera, voice recorder, diary and memory stick).

What's next?

- Two or three weeks later Cathryn will meet with you to talk about the information you provided.
  - If you would like there can also be an autism consultant at the meeting, or you can bring a friend.
  - We will use a digital voice recorder to record our discussion (If you agree)
  - We will talk about your fieldwork recordings – the GPS maps, voice recordings, photographs and anything you wrote in the diary.

- In this discussion you can tell us about your fieldwork experience.
- This meeting will be approximately 30 minutes to one hour long.

What will happen to the information I give you?

- Some of the information will be written down and given back to you a few weeks later so that you can read it and make changes or give us extra information.
- This is the information that we will use in a report to answer the questions we were asking at the beginning.
- You will have three weeks to check this information.
- Your name will not be used.

What if I have more questions about this study?

- Contact any of the research group members noted on Invitation 2.

What do I do if I would like to be involved in the study?

- Please keep 'Invitation 2' and the 'Information Sheet'
- In the envelope is a 'Participant Consent Form'.
- If you would like to be involved in the study please read through the information and then sign the form and email it to cathryn.kerr@utas.edu.au
- Or you can print the form, sign it, put it in the envelope and give it to Rose Clark.

Fieldwork Description and Advice Sheet

1

This study is about the public places and spaces in your town or city.

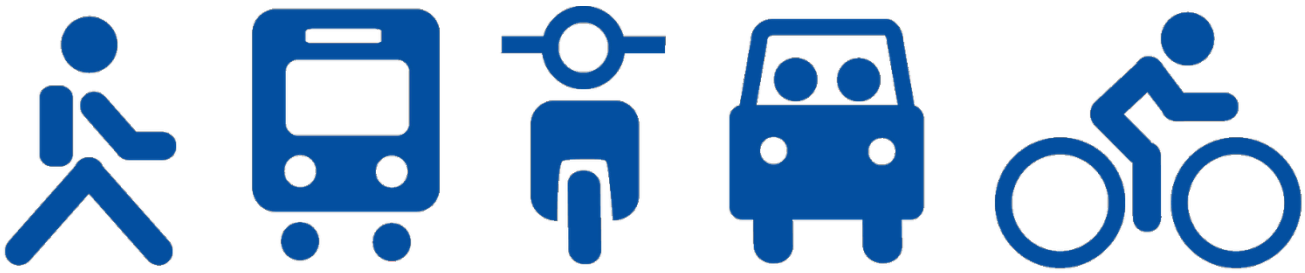
We want to learn about your experiences in them.

2

Use the GPS to map your daily routes through public spaces for seven days

- When you leave your house switch on the GPS.
- Switch off the GPS at the end of the day.
- If at any time during the day you do not want the GPS to be turned on you can switch it off and then back on again when you want to.

3 It does not matter if you do the same thing every day or different things.



- It does not matter if you walk, travel by bus, motorbike, car or bike - the GPS will collect information for all of these activities.

SAME

OR

different

- You do not have to do any different or special activities, or go to any new or different places.
- It does not matter if the places you go are:
  - Same places every day
  - Or new places

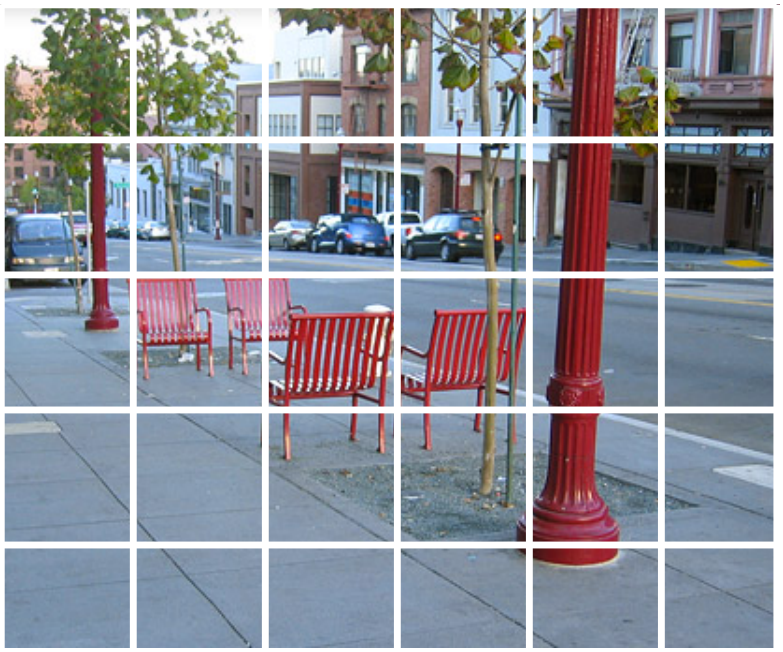
4 You can take photos of anything that is built as part of the spaces you are in

Photograph things that are:

- Interesting
- Annoying
- Curious
- Frightening
- Pleasant
- Funny
- Unusual
- Frustrating

You might like to take photos of:

- Buildings
- Parts of buildings
- Pathways
- Seats
- Steps
- Walls
- Gardens
- Artwork
- Lights
- Roads
- Space



Try not to photograph people's faces but it's OK if you do because we can still use the photos for discussion but they will have to be edited or deleted after that.

5

Use the digital voice recorder

- Record anything about your experience in the public spaces that you went to today

- Stop and take a break if this fieldwork activity becomes too difficult or makes you anxious or uncomfortable.
- You can tell the researchers if you do not want to keep doing the study
- If the equipment does not work properly, phone or email Cathryn Kerr
  cathryn.kerr@utas.edu.au 04 ....

Daily Fieldwork Notes

Day Number

1	2	3	4	5	6	7

Day of the week

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

Weather today

Sunny	Raining	Cold	Warm	Hot	Windy	Foggy

Please write an answer to the questions in the boxes provided, or you may like to record your answers on the digital voice recorder.

Question 1:

Are the public places you went through today places that you go through every day, or only sometimes, or are they new places?

Question 2:

Is there anything you want to tell the researchers about you experiences in the places and spaces that you went through today?

Semi-structured Interview / Discussion Process

Location: place familiar to and selected by each participant, first option being the room where regular group meetings are held

Purpose: to discuss the fieldwork recordings made by each participant

Intent: to give voice to the participant

Structure: use the participant's recordings to guide conversation about their experiences of public spaces –

1. Daily maps generated from GPS
2. Participant photographs associated with each day
3. Transcriptions of any voice recordings associated with each day
4. Written documentation associated with each day

Method:

- Discussion to be voice-recorded if participant agrees, handwritten notes if not
- Participant to be reminded of their ability to pause, move into a space away from the researchers for a break, or to terminate the interview
- Participant to be asked if there is anything within the space or the arrangement of items or people they would like to change, anything that makes them uncomfortable
- Participant to be asked to indicate how they will signal if they are begin to experience any anxiety or discomfort

Time allowance: 30 minutes estimated, but length of discussion to be determined by participant willingness and comfort

Procedure for handling participant anxiety or distress:

1. Suspend discussion / activity immediately
2. Suggest a break in proceedings
3. Suggest the participant move to another space outside of the interview area and from there determine if they wish to continue or suspend the discussion

Consent for follow-up questions – ASD / urban Design Study

- The researchers can contact me to ask more questions, or to clarify any information that I have already given them.

Participant's name: _____

Participant's signature: _____

Date: _____

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